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**Life Situation, Information Needs, and
Information Seeking in
Patients with Oesophageal Cancer
and their Family Members**

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*What lies behind us
and what lies before us
are tiny matters
compared to what lies within us.*

Ralph Waldo Emerson 1803-1882

ABSTRACT

This thesis explores the experiences of living with oesophageal cancer from the perspective of patients and family members. Also, their needs for information and how they seek information in relation to the illness were investigated. The thesis comprises one qualitative meta-analysis and three empirical studies including data from patients, family members, and health-care professionals.

Paper I was a qualitative meta-analysis the aim of which was to extend knowledge about patients' and family members' experiences of living with oesophageal cancer and clinically similar cancer forms, mainly head and neck cancer. As a result of the thematic analysis we have shown that both patients and family members 'run into an unpredictable enemy'. Patients had to 'endure a fading body'. Running into an unpredictable enemy and enduring a fading body led to 'entering social silence' for patients and family members.

The aim of **paper II** was to describe patients' experiences of living with oesophageal cancer and how they seek information in relation to the illness. Data was collected by qualitative interviews with thirteen patients and analysed by qualitative content analysis. The findings describe patients' experiences of receiving the diagnosis, their experiences of vague symptoms, and of existential concerns evoked by the illness. Undergoing investigations and treatment caused extreme tiredness. Patients experienced that the illness intruded upon their daily life. In order to manage the life-threatening illness, they sought information about the illness.

The aim of **paper III** was to describe family members' experiences of living with a patient suffering from oesophageal cancer, their information needs and information seeking. Data was collected by means of qualitative interviews with nine family members and analysed by qualitative content analysis. The findings describe that family members lacked awareness of the disease. When faced with the diagnosis, shock, stress, and disbelief were evoked. The cancer illness became intrusive into their everyday lives, routines, and life plans. Uncertainty about the course and prognosis of the disease was the main source of distress among them. In order to learn, obtain understanding for the illness, and manage this uncertainty, family members entrusted themselves to the experts and sought information from them.

Paper IV was a pilot study the aim of which was to describe patients' and family members' information needs following a diagnosis of oesophageal cancer, their satisfaction with information obtained, and health-care professionals' perceptions concerning patients' and family members' information needs. Data was collected by means of a study-specific questionnaire and analysed with descriptive statistics. The results indicate that patients' and family members' need for information following a diagnosis of oesophageal cancer was substantial and had not been adequately met by health-care professionals.

In conclusion, the receipt of the diagnosis of oesophageal cancer was an abrupt change from feeling healthy with vague symptoms to having a life-threatening illness. The illness disrupts patients' and family members' social world and relationships, and the whole family is affected. For understanding and managing the illness, they sought information from health-care professionals, social networks, and various media sources.

Keywords: oesophageal cancer, patients, family members, illness experiences, information needs, information seeking

LIST OF PAPERS

This thesis is based on the following papers referred to in the text by their Roman numerals:

- I. Andreassen S, Randers I, Ternulf Nyhlin K, Mattiasson A-C
A meta-analysis of qualitative studies on living with oesophageal and clinically similar cancer forms, seen from the perspective of patients and family members.
Submitted for publication
- II. Andreassen S, Randers, I, Näslund E, Stockeld D, Mattiasson A-C
Patients' experiences of living with oesophageal cancer.
Journal of Clinical Nursing 2006; 15:685-695.
- III. Andreassen S, Randers I, Näslund E, Stockeld D, Mattiasson A-C
Family members' experiences, information needs and information seeking in relation to living with a patient with oesophageal cancer.
European Journal of Cancer Care 2005; 14:426-434.
- IV. Andreassen S, Randers I, Näslund E, Stockeld D, Mattiasson A-C
Information needs following a diagnosis of oesophageal cancer; self-perceived information needs of patients and family members compared with the perceptions of health-care professionals: A pilot study.
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INTRODUCTION

Oesophageal cancer is a physically and emotionally devastating disease affecting the physical and psychological well being of patients (Tsottles & Reedy 2005). The disease also affects patients' quality of life (Blazeby *et al.* 2005, Brunelli *et al.* 2000, Gradauskas *et al.* 2006, Viklund *et al.* 2006b) and fundamental aspects of daily life such as the ability to eat and drink and socialise (Kirby 1999, Stein *et al.* 2005, Watt & Whyte 2003, Verschuur *et al.* 2006). Being diagnosed with oesophageal cancer means that relationships and communication within families are affected (Medvec 1988).

In my clinical work as a registered nurse with experience of surgical and oncological nursing, primarily within the upper gastrointestinal tract, my interest in studying this area arose when I met patients with oesophageal cancer who experienced troublesome physical symptoms, such as dysphagia (difficulty in swallowing), weight loss, pain, and fatigue. These patients were worried and raised questions about self-care, treatment and investigation procedures, and how this would affect them. I understood that they had a need to know and understand what was going on with them and to know what would happen to them.

I also met family members who were anxious about what would happen to the patients. The family members had a need for information about routines, procedures of investigation, and treatment, and most often how to assist and support the patients in the best way after discharge from hospital. I noticed that these family members, as well as the patients, were in need of psychological support.

As a nurse and being close to these vulnerable patients and their family members made me reflect upon their situation. Therefore, I wanted to get beyond the diagnosis and its symptoms and thereby get a deeper understanding of their situation. In reviewing the scientific literature, I came to understand that there was a scarcity of qualitative research exploring illness experiences from patients' and family members' own perspective.

This doctoral thesis contributes to knowledge and understanding of the life situation of persons with oesophageal cancer and their family members. When understanding these particular family's needs, health-care professionals will then be able to respond accordingly, and thus facilitate every day life. The introductory section is followed by a short presentation of relevant concepts and research pertaining to the topic of discussion. This thesis comprises one qualitative meta-analysis and three empirical studies. Unless otherwise stated, the term 'nurses' as used in this thesis refers to registered nurses.

BACKGROUND

Oesophageal cancer as a disease

Epidemiology and etiology

Oesophageal cancer is relatively rare in the western world. However, worldwide, this disease is the 8th most common cancer, and the 6th leading cause of death from cancer (Parkin *et al.* 2005). There are striking geographic variations in the incidence of oesophageal cancer (Corley & Buffler 2001, Parkin *et al.* 2005). Approximately 80% of all cases occur in developing countries, with China, southern and eastern Africa, and south central Asia as high-incidence areas (Parkin *et al.* 2005). In Sweden, oesophageal cancer is less common, with approximately 400 new cases annually (The National Board of Health and Welfare 2006).

A disease refers to problems related to the biological dimension such as alteration in structure and function. Concerning oesophageal cancer, there are two main histological types: squamous cell carcinoma and adenocarcinoma. Squamous cell carcinoma is the most common histological type, with tobacco smoking and high alcohol intake, especially in combination (Lagergren *et al.* 2000, Pera & Pera 2001), as the main risk factors in western populations. Another known risk factor for this type of oesophageal cancer is low intake of fruit and vegetables (Bosetti *et al.* 2000, Terry *et al.* 2001).

The incidence of adenocarcinoma of the oesophagus has increased in the western world throughout last decades. The strongest known risk factors for adenocarcinoma are gastro-oesophageal reflux (Farrow *et al.* 2000, Lagergren *et al.* 1999), Barrett's oesophagus (a columnar cell metaplasia in the distal oesophagus, associated with gastro-oesophageal reflux disease) (Kim *et al.* 1997, Lagergren 2005), and obesity (Lindblad *et al.* 2005, Wu *et al.* 2001).

Prognosis

Oesophageal cancer is an aggressive disease and has one of the poorest survival rates, independent of histological types, among malignant diseases. The prognosis is dependent on the stage of the tumour. The overall five year survival rate in Europe is 5-15% (Berrino 1999, Sundelöf *et al.* 2002). Despite a slight improvement in survival during recent years, the relative five year survival rate is still about 10% in most western countries (Enzinger & Mayer 2003, Sundelöf *et al.* 2002). Late symptoms and early metastatic dissemination are the main reasons for advanced disease at the time of diagnosis, which results in this poor prognosis (Allen *et al.* 1997, Patti & Owen 1997). The prognosis is also poor for those patients who have no signs of metastatic disease at the time of diagnosis and who are treated with intention to cure. Despite improvements in survival after oesophageal cancer surgery, the 5-year survival is still only about 30% (Rouvelas *et al.* 2005).

Clinical manifestations

In the early stage oesophageal cancer, patients demonstrate few if any symptoms. Dysphagia is the most common symptom, which is caused by narrowing of the oesophageal lumen. Because the oesophagus is an elastic and distensible organ, dysphagia generally occurs when the tumour obstructs more than half of the oesophageal lumen, generating symptoms relatively late in the disease. As the tumour growth proceeds, dysphagia becomes more predominant, and in the late stage there is severe dysphagia, when patients have difficulty swallowing their own saliva and if untreated, some patients succumb to aspiration pneumonia. Dysphagia is gradually progressive and may be described as food getting caught, throat fullness, chest pain or discomfort, or feeling of obstructions. Initially dysphagia is characterized by difficulty in swallowing solid foods and progresses to the point of inability to swallow liquids. Subconsciously, many patients adjust to these changes by altering their diets considerably, which results in significant weight loss (Brooks-Brunn 2000, Enzinger & Mayer 2003, McCarthy & Grem 2001). Other common symptoms may be loss of appetite, cough, bleeding, malaise, painful swallowing, vomiting, hoarseness (resulting from tumour overgrowth of the laryngeal nerve), and fatigue (Enzinger & Mayer 2003, Tsottles & Reedy 2005).

Diagnostic procedure and treatment

The only definite method for diagnosing oesophageal cancer is endoscopic with biopsy where histological examination of the biopsied tissue determines cellular differentiations (Tsottles & Reedy 2005). Several tests and procedures, such as computer tomography and endoscopic ultrasound, are used to determine the site, stage, and extent of the disease, as well as to determine which treatment is most appropriate for the patient. If the patient has lost 10% or more of the average body weight, a percutaneous endoscopic gastrostomy (PEG) is routinely used in some centres, with the aim of improving the patient's body weight and nutritional status prior to treatment, both oncological and surgical (Stockeld *et al.* 2001a).

Surgery is the standard treatment for resectable oesophageal cancer (Tsottles & Reedy 2005), with or without adjuvant oncological treatment. The surgery is extensive involving a lengthy post-operative recovery period. Unfortunately, more than 50% of the patients have either unresectable tumours or radiographically visible metastases at the time of diagnosis (Siewert *et al.* 2001) and are therefore not candidates for surgery. For these patients, the dominant treatment goal will be palliative, which consists mainly of the symptomatic treatment of dysphagia (Tsottles & Reedy 2005). Palliative techniques include self-expanding stents, laser therapy, and local radiation therapy. Other alternatives are chemotherapy and external radiation, separately or in combination (Stockeld *et al.* 2001b). Without palliative treatment, these patients suffer from weight loss and a rapid death caused by total dysphagia and aspiration of their own saliva. In recent years, chemotherapy and/or radiotherapy combined with surgery has been studied, unfortunately without resulting in significantly improved survival results (DeMeester 2006, Wu & Posner 2003).

Oesophageal cancer as an illness

Living with oesophageal cancer

As shown, patients diagnosed with oesophageal cancer face multiple symptoms and side effects of treatments and medication. However, the most distressing symptom is reported to be dysphagia (Bailey 2004, Hey *et al.* 2004) and eating difficulties (Viklund *et al.* 2006b), influencing not only the physical and emotional well being of patients but also their social life (Watt & Whyte 2003). Food is more than just nutrition; it has great cultural, emotional, and social significance and plays a major role in everyday life in all societies (Bailey 2004).

Nearly all patients with oesophageal cancer suffer from fatigue, which is distressing to both patients and families because it intrudes upon daily routines (Quinn & Reedy 1999), social activities (Verschuur *et al.* 2006), and it may necessitate the family to take upon extra practical duties (Plant 2001). Fatigue could be of greater concern for patients than pain, nausea, and vomiting (Stone *et al.* 2000). Fatigue has from a nursing perspective been described as “a subjective, unpleasant symptom which incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition which interferes with individuals’ ability to function to their normal capacity” (Ream & Richardson 1996, p. 527), and is not relieved by rest or sleep (Morrow *et al.* 2002).

Illness is the human experience of symptoms and suffering referring to how the disease is perceived, lived with, and responded to by the sick person and their family (Kleinman 1988). The understanding of the illness experience is essential when caring for individuals in the long-term. Recent studies demonstrate that patients’ quality of life is low after oesophageal cancer surgery (Gradauskas *et al.* 2006, Viklund *et al.* 2006b). Patients younger than 60 years are more emotionally affected compared to the older groups (Viklund *et al.* 2006b). The worst problem for patients after surgery is eating difficulties, followed by reflux, and dysphagia (Viklund *et al.* 2006b). Further problems are appetite loss, diarrhoea, and loss of weight (Blazeby *et al.* 2005, Verschuur *et al.* 2006, Viklund *et al.* 2006b). These physical problems have been shown to have a negative impact on patients’ abilities to perform social activities (Verschuur *et al.* 2006).

Knowing that cure is not possible, as is often the case in oesophageal cancer, triggers various emotions and adaptations, such as denial, anger, fear, and avoidance (Bailey 2004). The unpredictability of the future is experienced as problematic. Fear for physical suffering, metastases, and fear for death are reported to be commonly experienced psychological problem in patients with oesophageal cancer (Verschuur *et al.* 2006). The impact of cancer on an individual is a profound and life-changing experience not only for the patient but also involving the whole family (Plant 2001).

The concept of family

The concept of 'family' is difficult to define and has a different meaning for each individual. A patient might have stronger bonds to persons outside the nuclear family. It is therefore natural to broaden the concept of family to include persons that have a significant importance to every member of the family. One definition that has been used is "a family is who they say they are" (Wright & Leahey 2000, p. 70).

Consequently, a family consists of a number of individuals with strong bonds to each other, and family members might thus be children, spouses, close friends, neighbours, colleagues etc.

The significance of family for health and sickness, and for good nursing, has been highlighted by Wright and Leahey (2000). These authors apply the general systems theory to the understanding of families by health-care professionals, as introduced by Bertalanffy in 1936. Family is a system characterised by a complex of elements in mutual interactions. This definition allows us to view the family as a unit and to focus on the whole family instead of focussing on the family members individually. The family is a whole, but at the same time a part of a suprasystem, e.g. neighbourhoods or organisations, and in turn is composed of many subsystems, e.g. parent-child, siblings, or marital systems. Therefore, it is valuable in nursing care to initially consider who the family is, the significant subsystems of the family, and some of the important suprasystems to which the family belongs (Wright & Leahey 2000).

Relationships within the family are dynamic and the diagnosis of cancer in one member will affect the whole family, changing the relationship with the person who has cancer and with one another (Plant 2001). However, each member of the family might experience the situation differently (Kirkevold 2003). This is very much depending on factors such as the relationship an individual has with the person who has cancer, as well as the age and role of the sick person in the family (Corner 1997). Research has shown that social, practical, and emotional support from family is essential when a person is in distress. This support has the possibility to prevent illness, promote recovery, and adaptation of the new situation (Kirkevold 2003).

The family and the patient

When a person in the family has cancer, the whole family must deal with a number of challenges within: the family, the cancer itself, the treatment, and the available support networks (Plant 2001).

Certain cancer diseases, such as oesophageal cancer, are regarded as deadly diseases. The close family members will experience distress to different extents. Life may change fundamentally for many family members as a result of the diagnosis of cancer; for example giving up work, curtailed social activities, or changed roles and relations within the family. These fundamental changes may influence the family's lifestyle, it may for instance be difficult to plan holidays and the family may experience financial difficulties. Changes in life could also be less apparent, such as

uncertainty about the future and the loss of their perceived future (Cooley & Moriarty 1997, Lewis 2006, Morse & Fife 1998, Wideheim *et al.* 2002).

Living with a person with cancer means that a whole family could be faced with fear and anxiety (Wideheim *et al.* 2002) originating from uncertainty of the cancer nature (Shaha & Cox 2003), side effects of cancer treatment, distress, and hopelessness (Ferrell *et al.* 2002, Lewis 2006, Wideheim *et al.* 2002). Moreover, distress in family members is experienced as great or greater than in the person who has cancer and that they may express more fear of death than the person with cancer himself (Ferrell *et al.* 2002, Northouse *et al.* 2000). They are frightened about what will happen to the person with cancer but also for being left behind. In the family feelings of loneliness might be aroused because the family members do not have anyone to share their feelings with about the illness, and they are afraid how the future will turn out (Grbich *et al.* 2001).

Family member experience that the ill person in the family tries to protect them by keeping them outside or by not involving them. Plant (2001) highlights that family members are often better prepared to handle their situation if they are aware of what is happening.

Information needs and information seeking

Information needs

A fundamental aspect of cancer therapy is appropriate information to patients and their family members (Carlsson 2000, Eriksson & Lauri 2000, Rees & Bath 2000) since they have considerable needs for information after receiving a diagnosis of cancer (Chapman & Rush 2003, Harris 1998, Morris & Thomas 2002, Rutten *et al.* 2005). According to Brashers *et al.* (2002, p. 259), information can be defined as “stimuli from a person’s environment that contribute to his or her knowledge or beliefs”. Mills and Sullivan (1999) and Jenkins *et al.* (2001) report that the large majority of people with cancer want to know more about their disease, its diagnosis, treatment options, side-effects, clinical options, self-care, and how to return to a normal life. It is clear that patients and family members prefer information that is tailored and personalised to their specific needs rather than generic which can lack relevance (Leydon *et al.* 2000).

Oesophageal cancer has a dismal prognosis and survival is less likely than many other cancer diagnoses. Nursing care in this specific cancer diagnosis involves information to patients and their families (Mackenzie *et al.* 2004, Medvec 1988, Quinn & Reedy 1999). The sparse research about information needs among these patients, emphasises that they want information about the disease and that those who had undergone a total thoracic oesophagectomy require considerable information both pre- and postoperatively. Information about what to expect in the future is another central issue (Gregoire & Fitzpatrick 1998), particularly the first six months following surgery (Verschuur *et al.* 2006) and as a part of the rehabilitation process in oesophageal cancer (Gimigliano *et al.* 2005).

Information seeking

Information management comprises communicative and cognitive activities such as seeking, avoiding, providing, appraising, and interpreting the environmental stimuli contributing to knowledge or beliefs (Brashers *et al.* 2002). Lazarus and Folkman (1984) stress that information is important in order to cope with a threatening situation. Adequate, appropriate, and well-timed information can help decrease anxiety and illness-related uncertainty in patients and family members (Brashers *et al.* 2002, Harris 1998), and facilitate adjustment and coping (Harris 1998, Lazarus & Folkman 1984).

Johnson and Meischke (1991) distinguish between two modes of information: (1) interpersonal sources, involving face-to-face interactions with for instance friends, family, and health-care professionals; and (2) mass media sources, involving print and electronic media. Mass media sources are effective when providing fairly general information to a large audience quickly. Interpersonal sources are viewed as more effective in reducing illness-related uncertainty. This is because they, in addition to information, provide social support.

Patients and family members seek cancer related information both from mass media and interpersonal sources (Carlsson 2000, Mills & Davidson 2002, Rees & Bath 2000). The absence of readable and understandable written information leads patients to seek other sources that are not always reliable or are not designed to address their needs (Balmer 2005). The Internet is a growing source of information for patients and family members (Norum *et al.* 2003), however, those with the greatest need of information often have the poorest access (Balmer 2005) or do not have the confidence to use this technology (Ziebland *et al.* 2004). In addition, they still rely on physicians, oncologists, and friends as their key sources of information (Chalmers *et al.* 2003, Norum *et al.* 2003, Rees & Bath 2000). Carlsson (2000) reports that patients actively seek information about cancer only to a limited degree from sources outside the health-care system. However, when cancer issues are presented in the mass media, the majority of patients are interested.

Consultant surgeons and fellow patients are found to be key sources of information (Mills & Sullivan 1999). However, patients' sources of information change throughout different phases of the cancer illness. Jenkins *et al.* (2001) have reported that patients who are well informed are better able to understand and participate in their health-care than those who are falsely informed or underinformed. Further, well-informed patients experience less anxiety and are more likely to cope with their illness than others. Family members tend to feel underinformed (Morris & Thomas 2002). Nurses and physicians tend to underestimate family members' needs (Bijttebier *et al.* 2001).

Age has been found to be a significant factor in seeking information, in that younger people require more information than older people (Bilodeau & Degner 1996). These authors discuss that this may not be due to younger people having

greater information needs, rather, younger people tend to seek information more actively, while older people assume a passive role.

Exchange of information between health-care professionals and patients contributes significantly to the overall satisfaction of care (Kavadas *et al.* 2004). Watt and Whyte (2003) stress that lack of information in patients suffering from dysphagia due to oesophageal cancer resulted in unnecessary anxiety for the patients and thus affecting their quality of life.

RATIONALE

The focus of medicine and nursing has gradually shifted during the past two decades from an outsider perspective to an insider perspective focusing on the sick person's own experiences of living with an illness (Thorne & Paterson 1998). Research of this genre focusing on processes and issues related to health and illness has been largely qualitative, relying primarily on in-depth, open-ended interviews. This has contributed to a considerable store of research describing health and illness experiences from a subjective perspective (Paterson *et al.* 2001).

Oesophageal cancer affects the physical and psychological well being of both the patient and the family, and there is a substantial need for information after receiving a diagnosis of cancer. Thus, an important aspect of care is information to patients and their family members, which should be tailored according to a knowledge base derived from the lived experiences of patients and family members.

Yet, there is a scarcity of studies exploring the experiences of living with oesophageal cancer from the perspective of patients and family members. Their needs for information and their interests in seeking information in relation to the illness have not been sufficiently studied.

AIMS OF THE THESIS

The overall aim of this thesis is to generate knowledge and understanding about patients' and family members' life situations with regard to how they experience living with oesophageal cancer, their need for information, and how they seek this information. The specific aims were:

- I. to extend knowledge about patients' and family members' experiences of living with oesophageal cancer by including other upper gastrointestinal, and head and neck cancer.
- II. to describe patients' experiences of living with oesophageal cancer and how they seek information.
- III. to describe family members' experiences, information needs and information seeking in relation to living with a patient suffering from oesophageal cancer.
- IV. to describe information needs following a diagnosis of oesophageal cancer of patients and family members, as well as health-care professionals' perceptions concerning information needs; and patients' and family members' satisfaction with the information received.

Table 1. Overview of the papers

	Paper I	Paper II	Paper III	Paper IV
Aim	To extend knowledge about patients' and family members' experiences of living with oesophageal cancer by including other upper gastrointestinal cancer and head and neck cancer.	To describe patients' experiences of living with oesophageal cancer and how they seek information.	To describe family members' experiences, information needs, and information seeking in relation to living with a patient suffering from oesophageal cancer.	To describe: (1) information needs following a diagnosis of oesophageal cancer of patients and family members, health-care professionals' perceptions concerning information needs; and (2) patients' and family members' satisfaction with the information received.
Method/design	Qualitative meta-analysis	Qualitative descriptive study	Qualitative descriptive study	Descriptive, comparative study
Data sources (n=)	13 qualitative original research reports	13 patients	9 family members	15 patients 16 family members 18 registered nurses 9 assistant nurses 7 physicians
Data collection	Systematic database searches in Medline, Chinal, PsychInfo, and Swemed, and examinations of reviews and reference lists	Qualitative interviews	Qualitative interviews	Study-specific, self-administered questionnaire
Data analysis	Thematic analysis	Qualitative content analysis	Qualitative content analysis	Descriptive statistics Rank-invariant non-parametric test

METHODS

Since nursing practice is based on a diversity of knowledge, nursing research requires various types of methods in order to answer different questions depending on their nature. In this thesis, qualitative methods are used in papers I-III since qualitative methods are a way of approaching the empirical world (Taylor & Bogdan 1998). Moreover, a central feature is that qualitative methods proceed from people's own perspective, how they experience their reality and act in their everyday life (Taylor & Bogdan 1998). Data collected in qualitative research are obtained mainly from people's own spoken or written words, interviews (paper II, III), document analysis (paper I), and observations (Patton 2002, Taylor & Bogdan 1998). Paper IV is a quantitative, nonexperimental study with empirical data gathered through questionnaires.

Paper I: A qualitative meta-analysis

To extend knowledge on how patients and their family members experience living with oesophageal cancer we found it suitable to carry out a meta-analysis since the approach allows interpretation of findings deriving from a diverse set of studies into one another and into the possibility of a coherent new whole (Paterson *et al.* 2001).

The term qualitative meta-analysis was first used by Stern and Harris (1985) referring to the synthesis of findings from a group of qualitative research into one explanatory interpretative end product. Terms used to describe the synthesis of qualitative research findings include many terminological labels, e.g. 'meta-study', 'meta-analysis', and 'meta-synthesis' (Finfgeld 2003). There is no consensus in the literature about which terms to use (Thorne *et al.* 2004), however, Paterson *et al.* (2001) clearly differentiate between the processes of analysis and synthesis. They argue that a meta-synthesis involves synthesising not only the findings, but also the methodological and theoretical perspectives of the primary research as well as considering the historical and sociocultural context in which they occurred. The term 'meta-analysis' is used throughout this paper since the intention was to analyse solely the findings of the original reports.

As there were few studies dealing with experiences of living with oesophageal cancer, the inclusion criteria were broadened to comprise other upper gastrointestinal cancers (mainly head and neck cancer) because survival and palliative clinical questions (mainly involving food intake) are similar between the cancer forms (Homs *et al.* 2005, List & Bilir 2004a, b).

The research team

Meta-analysis is a team effort (Paterson *et al.* 2001). Apart from myself, our team consisted of three senior lecturers in nursing and researchers, skilled and experienced in the use of qualitative methods, because in a meta-analysis there is a need to have

variation in expertise in order to be able to apply multiple perspectives and reflect about these perspectives (Paterson *et al.* 2001). All team members were involved in all aspects of the research process, however, for practical and educational reasons, I had the main responsibility for planning and completing the project. We began the project by reading Paterson *et al.*'s (2001) practical guide to meta-analysis in which the authors describe their experiences with a meta-study research project on chronic illness. After taking part in the authors learned experiences the team met for discussions and started planning the process of carrying out the meta-analysis.

Locating research reports

Research reports for a meta-analysis are generally located by several search techniques (Paterson *et al.* 2001). The techniques that are the most commonly used were applied, i.e. computer searches of reference databases and examination of reviews (cf. Paterson *et al.* 2001). In addition, manual searches of reference lists in textbooks of oncology, reference lists to reports included, and those of reports that were excluded through the appraisal procedure. Finally, all 'related articles' in Medline for those reports that are included in the meta-analysis were examined.

The sources of data were the international databases Medline (accessed via Pubmed), Chinal, PsychInfo, and the Swedish database Swemed. Before performing the searches, I did several test searches in order to discover the most productive set of search terms. As these test searches were not limited regarding publication date or journal subset, the searches resulted in a large amount of unrelated medical reports not linked to the aim. For that reason, the searches were then limited to nursing journals, resulting in a manageable amount of reports.

The searches were performed during November-December 2005. The following search terms were finally used and adapted to the prerequisites of each database: upper gastrointestinal tract, neoplasms, head and neck neoplasms, liver neoplasms, oesophageal neoplasms, pancreatic neoplasms, biliary tract neoplasms, stomach neoplasms, psychological adaptation, emotions, psychological stress, need, experience, and emotion. A combination of thesaurus terms and free-text terms was used. The searches were limited to nursing journals but not regarding publication date.

Inclusion criteria

In this meta-analysis, the inclusions criteria were that the reports had to be published in peer-reviewed journals and to be qualitative original reports written in English or in any of the Scandinavian languages, focusing on the experiences of living with oesophageal and clinically similar cancer forms seen from the perspective of patients and family members. If any reports used mixed methods, the qualitative findings had to be separable from the quantitative findings. Sandelowski and Barroso's (2003, p. 154) definition of what a qualitative study is has been used throughout the process of locating research and inclusion: "empirical research with human participants

conducted in any research paradigm that used what are commonly viewed as qualitative techniques for sampling, data collection, data analysis, and interpretation.”

The electronic searches revealed more than 150 original reports. I reviewed these first by title, then by abstract, and finally by full text. Those that did not meet the inclusion criteria were excluded at each stage. This left 23 reports, which were evaluated by two team members guided by the Primary Research Appraisal Tool developed by Paterson *et al.* (2001). In two cases, the authors of the original reports were contacted by e-mail when it was unclear which cancer diagnosis was included. These contacts resulted in exclusion of the reports concerned. After further appraisal and discussion within the team, a further eight reports were excluded for reasons that the focus in these reports did not match the aim of our meta-analysis or lacked original research results. Thirteen reports, comprising studies from eleven projects, met the inclusion criteria and were included in this study.

Thematic analysis

The aim of analysis in a meta-analysis is according to Finfgeld (2003, p. 894) “to produce an integrative interpretation of findings that is more substantive than those resulting from individual investigations”. This can be done by various approaches. Paterson *et al.* (2001) state that any interpretive method that is typical for analysing data in qualitative primary research is also applicable for a meta-analysis, depending on the purpose. We applied a thematic analysis, as described by Patton (2002), since we wanted to go beyond the descriptive data of the original reports and elucidate and interpret its core meaning.

Before starting the analysis process, we decided what textual elements or units of data in the findings of the original reports that should be processed (cf. Paterson *et al.* 2001). Only broadtext and quotations in the findings should be analysed, not headings/categories/themes or text that referred to other research. Only those parts of their findings that related directly to our aim were included.

As recommended by Patton (2002), we began the analysis by reading each report independently in order to obtain a sense of the whole content. Key phrases, i.e. a string of words, a sentence, or several sentences bound together by their content or meaning, that related to the aim were defined directly in the original reports. Each key phrase was copied and pasted into a word processor where after a descriptive code was given and an explanation clarifying its context (see Table 2) in order to retain the meaning of the phrases when they were removed from the original context of the reports.

Table 2. Example of a code and key phrase within its context

Sample	Patients
Context	Three months after the operation for gastrointestinal cancer
Code	Abandoned
Key phrase	when nothing but loneliness was there, patients felt abandoned
Report	Olsson <i>et al.</i> 2002a

In this way we could easily examine the key phrases in the light of the context of the original report and check our coding, categorisation, and interpretation. All codes were compared to each other and those that appeared to belong together were grouped into preliminary categories. The accuracy of these preliminary categories was verified by working back and forth between the data and the classification system.

Finally, we examined, compared, and interpreted the data within the descriptive presentation, determined the essential features of the categories and extracted the underlying meaning related to the research question. Throughout this interpretive process, we tested various interpretations by seeking and discussing explanations other than our initial versions. Lastly, we formulated three themes, i.e. threads of meaning that recurred in category after category (Baxter 1991).

Papers II and III: Qualitative descriptive studies

Persons in the studies

In studies based on qualitative data, statistical power, sample size, and generalization of results are not the focus (Kvale 1996). Since the purpose of sampling was to maximize the information (Streubert & Carpenter 1999) and thus maximize understanding of a phenomenon (Polit & Beck 2004), the selection of participants was of major interest (Patton 2002). Therefore, the participants had to be selected purposefully, to benefit analysis. One of several different strategies for purposefully selecting is to include cases that meet some predetermined criterion of importance (Patton 2002). In order to achieve as broad and varied description as possible of their illness experiences, patients in paper II were chosen to represent both men and women of various ages who had undergone different treatment modalities for oesophageal cancer. Moreover, the patients should feel sufficiently well enough to participate in an interview.

The sampling procedure went as follows: In collaboration with the surgeon in charge of the patients' medical care potential participants were identified based upon earlier mentioned criteria. They were contacted by sending a letter informing about the aim and procedure of the study, stating that participation was voluntary, that they had the right to withdraw at any time, and that their privacy would be protected by not revealing names and other identifiable features when reporting the findings (Hermerén 1996). The patients were also asked to consider if they had a family member or other close person that they thought would be interested to participate in the study. After about one week, I telephoned the patients and repeated the information given in the former letter. If the patients agreed to participate, time and place was set for the interview. When all patients on the list of the potential participants had been contacted and interviews had been carried out with those who consented, there was a need for further data collection as sampling and data collection had not come to the point of redundancy (Patton 2002), i.e. at the point of which no new information was forthcoming. The surgeon was again contacted and new names were added to the list.

In total, seventeen patients were contacted (whereof two pilot-interviewees). Three of the patients declined due to their bad state of health and one could not be reached. Considering participation of a family member, two of the patients declined to give names of family members to be interviewed. Names and telephone numbers was received from the patients for those family members who they had chosen. Their participation was confirmed by telephone and a time and place was set for the interview based on their preferences. The same written and oral information was given to them as to the patients.

After thirteen interviews with patients; six women and seven men, and nine interviews with family members; one brother, two husbands, and six wives, data collection had come to the point of redundancy, and thus, the recruitment ceased (Patton 2002). Patients' ages ranged from 44 to 77 years. Age was not ascertained for the family members, however as a descriptor, five of them had full-time or part-time employment and four were retired. Some of the patients and family members had young children and adolescents.

Qualitative interviews

The method for data collection in papers II and III was qualitative interviews, which assert that people are experts of their experiences and the best ones to report how they experience a particular event or phenomenon (Darlington & Scott 2002). The purpose of these interviews was to gain rich and deep information, and to enter into people's subjective perspectives (cf. Patton 2002). Patton (2002) describes different basic approaches for collecting qualitative data through qualitative interviews. The method used in papers II and III is what he describes as the general interview guide approach, also called semi-structured interviews by Kvale (1996). Both these methods are characterised by predetermined issues where the interviewer is free to choose the phrasing and order of the questions.

An interview guide can be more or less detailed depending on the research questions and aim of the interview. With a less detailed structure, that which was of value might not have been captured, and a too detailed guide might not have provided enough flexibility and decreased the interaction in the interview situation, and thereby might have made me less sensitive to individual and situational differences. In papers II and III, the following topics were outlined in the guide (see Table 3), which was used to ascertain that all topics were covered.

Table 3. The interview guide

Main topics	Content of the topics
Experiences	Patients' experiences of living with oesophageal cancer. Experiences of receiving the diagnosis, undergoing investigations, and treatment. The effect of the illness on every day life for patients and family members.
Information needs	What is important for patients and family members to know about the illness?
Information seeking	If patients and family members want to know about the illness, what are their sources?
Confronting health-care professionals with information	Patients' and family members' experiences of confronting health-care professionals with information they have found.

Pilot interviews

As a first step in the data collection phase, two pilot interviews with patients were carried out in order to evaluate the interview guide (Table 3), to determine the length of time it would take to perform the entire interview, and to determine whether the patients felt that the time and inquiry was too burdensome. After interviewing I transcribed the audio recorded interviews and discussed the transcripts with one of my research supervisor. The pilot interviews were included in the study because we found that they had turned out well, i.e. data obtained were rich and of good quality. Only minor semantic and layout revisions were made in the interview guide. As a result of the pilot interviews, which lasted about one hour, it was judged that the interview process was not too burdensome for the patients.

Interview process

The interviews were conducted between December 2003 and March 2004. They all started with a warming up phase which included creating a relaxed and conversational atmosphere for the further interaction between the participant and myself. Establishing a trustful relationship was important since the aim was to collect rich data (cf. Randers 2002). I was often invited by both patients and family members to have some refreshments, which further contributed to develop a relaxed atmosphere.

The formal start of the interview included informing the participants once more about the study. They all consented to having the interviews audio recorded with a small pocket-size recorder. Thereafter the interviews continued with the following invitation to the patients: "Please, tell me about your experiences about living with oesophageal cancer"; and for family members: "Please, tell me about your experiences of your wife's/husband's/brother's illness". During the conversation some patients suffered from pain and fatigue, and both patients and family members were sometimes emotionally affected while talking about their illness experiences. I tried to be very attentive to what was ongoing during the interview, turned off the

tape recorder and took a break, and then asked if they would like to terminate the interview, but they all declined.

Rounding off the interview, the participants were asked if there was something further they wanted to add or talk about. Some expressed their thanks for the possibility to tell their story. It appeared that they had appreciated meeting someone who had time and interest in listening to them. One family member said: “The most I have ever talked about the illness, I have perhaps done today during the interview”. Further, participants explicitly told me that they had participated to contribute to the knowledge about this illness so that others in the same situation would benefit in the future, as also shown by Friedrichsen (2002) and Mattiasson (1995).

On one occasion after the interview had ended and the tape recorder was turned off, the participant continued telling about experiences that was considered being of importance. After receiving consent, the tape recorder was turned on again.

Out of respect for the participants, both patients and family members were given the possibility to choose time and place for the interviews. Ten interviews with the patients were carried out at their homes (including the two pilot interviews), one in a suitable room at a hospital, one at my office, and one in a separate place at a café where the patient’s privacy could be protected. Concerning interviews with family members, six interviews were carried out at their homes, two at my office, and one in a suitable room at a hospital. In most cases, the family member chose the same day and place as the patient. In those cases, the interviews were held separately. No specific request was made as to whom to interview first. The order of priority was decided by the patients and family members before I met with them. There was a potential risk that it could be difficult to have focus on the interview and be a good listener. However, between the two interviews, a break was made which gave time for social conversation, where after the next interview started. In one single case, the spouse entered the room during the interview with the patient, expressing that she wanted to listen to her husband. I asked her husband if that was okay with him. He answered: “Yes, oh yes! You don’t need to ask that question.” Having her sitting down in the same room, listening and sometimes commenting what was said, did not influence data collection in a negative way. She made some elucidations, but not questioning what he said.

All interviews were tape-recorded which allowed for a better possibility to capture more from the interviews than otherwise would have occurred by relying only on memory or notes. The interviews with the participants lasted between 20 and 90 minutes, most of them lasting about one hour.

Qualitative content analysis

After the interviews, I transcribed them verbatim, which means that no interpretation was made during the transcription. This was done parallel with data collection as time allowed. After all interviews were transcribed, I listened to all tapes simultaneously with reading the transcripts. The transcriptions were found to be of good quality.

Papers II and III had a qualitative descriptive design. Qualitative content analysis was chosen, which according to Sandelowski (2000), should be applied when a description of phenomena is desired.

Currently, there are two main approaches in content analysis. One is the quantitative approach used for instance in media research. And the other is the qualitative approach often used in nursing research. Apart from describing elements that are physically present in the text, i.e. manifest content analysis, this method has expanded to include interpretation of the underlying meaning of the physical data, i.e. latent content analysis (Graneheim & Lundman 2004). In recent years, qualitative content analysis method has become commonly used in qualitative nursing research (Hertzberg 2002, Häggström 2005, Hörnsten 2004, Randers 2002, Söderberg 1999).

According to Berg (2004, p. 269), content analysis is “a passport to listening to the words of the text and understanding better the perspective(s) of the producers of these words”. Berg (2004) states that in content analysis, both induction as well as deduction can be used. In paper II the qualitative content analysis was conducted inductively (Berg 2004), and in paper III, we combined an inductively and deductively approach (Berg 2004), where data involving the illness experiences was analysed inductively.

The inductive process went as following: The transcripts of the interviews were carefully read to gain an overall understanding of the illness experiences described by the patients and their family members. Thereafter, the text was re-read thoroughly, bearing the aims of the papers in mind. During this reading, the text was divided into units of content directly in the text. These units could be either a part of a sentence, a simple sentence, or several sentences bound together by their content. The following text is an example of a unit of content, which describes one spouse’s experience:

I don’t think anyone has ever asked how old our children are, if they attend school or anything like that. They [health-care professionals] don’t see seem to care that there is a family around the patient and that we in fact have a sixteen-year-old son, who has grown up with this.

The content of this unit was given the code ‘There is a family around’ written directly in the margin labelling the content. Then this coded unit was transferred into a new document using the computer’s word-processor. The code was compared to other similar codes and grouped and classified under the category ‘Children’.

The content of this category was compared to others looking for differences and similarities. This process led to development of main categories, in the present case the main category of ‘Intrusions on family’.

The process of the deductive analysis (Berg 2004) in paper III was as follows: The units of content were identified related to the model of information sources in communication research described by Johnson and Meischke (1991) (see page 7 in the thesis), marked, and sorted into suitable categories of information sources.

The categorisation was continuously discussed between two of the co-authors and me and important insights, which emerged from the different way we looked upon the same data, led to consensus of the categorisation.

Finally, to increase trustworthiness, the transcribed interviews were re-checked to determine if the presentation of the findings gave justice to the participants' stories. The presentation was deemed to be in accordance with their stories.

During the interviews, the participants agreed to the use of direct quotations from the data collected. To be complete in data reporting and to illustrate the research findings as well as the authors' interpretations of its content (Berg 2004), the most representative quotations are used, as argued by Sandelowski (1994). We have made certain linguistic and grammatical revisions of the quotations, since it may be difficult to read and understand spoken language in a written format (Kvale 1996, Sandelowski 1994). The meaning has not been distorted or misrepresented as emphasised by Sandelowski (1994). Our approach to editing the quotations has been to be faithful to what the participants expressed and our own ideas concerning what the quote represents. We have attempted to stay as close to the text as possible by using words and expressions from the patients' and family members' stories, since one feature of qualitative descriptive studies is to offer a comprehensive summary of an event in the everyday language (Sandelowski 2000).

Paper IV: Descriptive, comparative pilot study

Sample and data collection

The sample in paper IV included patients with oesophageal cancer, family members, and health-care professionals, i.e. registered nurses, assistant nurses, and physicians, who provided care for this group of patients. The specific inclusion criteria for health-care professionals were, besides that they should be qualified within their professions, that they should have experience of working with patients with oesophageal cancer care for a minimum of one year. To be included all patients and family members provided informed consent to participate in the study and had to be able to read and understand the Swedish language. In addition, they had to be physically and psychologically capable of participating and resided in their own home. Furthermore, patients should have received the diagnosis of oesophageal cancer within the previous 2-4 weeks.

Consecutive patients, who met the inclusion criteria at one inpatient clinic and two outpatient clinics, were asked by a clinic nurse/physician when consulting the physician prior to surgical or oncological treatment, if they would be willing to fill in the self-administered, study-specific questionnaire. Those who agreed to participate received an information letter informing that participation was voluntary and that their privacy would be protected. A stamped addressed envelope was enclosed along with a cover letter asking them to complete the questionnaire at home within two weeks. Most of the patients were accompanied by a family member at this meeting.

After consent from patients, family members were asked to participate and a letter with the same content as the patients received was given to those who accepted.

Altogether 15 patients and 16 family members participated and filled in the questionnaires. A total of 34 health-care professionals participated with 18 registered nurses, 9 assistant nurses, and 7 physicians.

Study-specific questionnaire

The study-specific questionnaire used in paper IV was designed to address patients' and family members' information needs following a diagnosis of oesophageal cancer, their satisfaction with information received, and health-care professionals' perceptions of patients' and family members' information needs.

In order to develop the questionnaire, textbooks, and published research about oesophageal cancer were reviewed in order to learn about the diagnosis, its specific symptoms, investigations and treatment procedures, and specific information needs that could be related to these aspects. A list of various topics found to be of weight was then created. Secondly, qualitative interviews with three patients with oesophageal cancer and three family members were carried out. They were asked about what they considered to be important for them to know in relation to the diagnosis. These interviews were analysed analysis where the aim was to identify topics of importance, which were added to the list constructed after reviewing the literature. Based on the various topics, items (i.e. questions/statements) were formulated. For inspiration when it comes to wording of items the 'Toronto Informational Needs Questionnaire – Breast Cancer' (TINQ-BC) (Galloway *et al.* 1997) was used. Some of the items in TINQ-BC were translated into Swedish. These items were generic in nature and were therefore considered relevant for oesophageal cancer. These items were added to the list. This constituted the basis upon which a preliminary questionnaire was constructed.

Related items were grouped together by topic area. These formed subscales. The final version of the questionnaire consisted of 64 items divided into seven subscales (see Table 4).

Table 4. Overview of subscales and their content

Subscale	Nr of items	Content
Anatomy/physiology	2	How the digestive system works and looks like
The illness	14	The disease, its symptoms, process and prognosis
Tests/treatment	10	How and why different tests/treatment are done, how to prepare for them, how the patient will feel during and after them, complications and possible side-effects, and advantages/disadvantages with treatment
Information methods	8	Different interpersonal and media sources of information
Self-care	13	How the patient can take care of himself in relation to medication and nutrition
Psychosocial aspects	10	How to obtain assistance in dealing with feelings and concerns arising as a result of the illness
Health-care professionals competence	7	What help and support different health-care professionals can assist the patient/family member with

The response alternatives were measured on a four point Likert scale with the alternatives: not important (1), important (2), somewhat important (3), and very important (4). There was also the alternative ‘not applicable’. In addition, the participants were requested to state how satisfied they were with the information received related to each item. Satisfaction was measured on a three point Likert scale with the alternatives: not satisfied (1), somewhat satisfied (2), satisfied (3).

Three additional preliminary questionnaires were thereafter developed where the wording of the items was adapted to suit family members and health-care professionals. These preliminary questionnaires were then assessed by three clinical experts, i.e. specialist surgeons and specialist surgical nurses experienced in working with patients with oesophageal cancer, who commented on content, wording, and relevance of specific items. Items that they found to be duplicative, unnecessary, or unsuitable were deleted from the questionnaire. Revisions were also made in relation to what they considered difficult to understand. Thereafter, they were asked to evaluate the revised questionnaire on relevance and completeness of the questionnaire. Content validity is important when a questionnaire is being developed (Shea & Fortna 2002), which in paper IV means how adequately the items match the concept being measured. The clinical experts judged the items in the questionnaire to be representative to questions that could be asked about information needs in oesophageal cancer. Based on their judgement the questionnaire was judged to have content validity (cf. Shea & Fortna 2002).

Finally, the questionnaires were pre-tested for relevance and to check the time it would take to fill them in, with participants representative for paper IV, i.e. two patients, two family members, three registered nurses, one assistant nurse, and two physicians. The results from the pre-test are not included in the results of paper IV. Some semantic changes were made after this pre-test. A few examples of items can be seen in Table 5.

Table 5. Examples of statements from the patients’ questionnaire

Item	It is important for me to know...
3	why I have difficulties in swallowing
20	how I will feel during tests/treatment
53	how to choose food that help me retain my weight

Statistical analyses

In the statistical analyses of paper IV, the statistical software Statistica 7.1, SAS 8.2, and Excel 2000 were used. Despite the limited sample size, descriptive statistics, i.e. mean value, were used to present data in order to compare the different sample groups. Twenty-eight items were identified where the variation in patients’ and family members’ ratings appeared significant. A rank-invariant non-parametric test (Svensson 1998) was performed on these items. This test is suitable for paired ordered categorical data and is analogous to the Mann-Whitney *U*-test used for unpaired data. The test measures the systematic differences between two ordered categorical judgements without assumption regarding distribution. Relative position

(RP) shows if there are any systematic differences in position on the scale by calculating the differences between the probability of the ratings by the patients being higher or lower than that of the family member. Relative concentration (RC) shows systematic differences in concentration by calculating the differences between the probabilities of the distributions of the responses on the rating scale. Possible values of RP and RC range from -1 to 1 and values close to zero indicate negligible differences between the different groups. In this study, a negative RP indicates that family members report a higher importance to the information needs than patients. The negative RC indicates that the distributions of the responses for family members were more concentrated than for the patients.

A confidence interval of 95 per cent was considered statistically significant. If zero was not included, statistical significance was accepted.

ETHICAL CONSIDERATIONS

In each step of the research process, ethical considerations need to be addressed. In research involving humans, as often in nursing research, caution must be taken to protect the rights of those individuals (Hermerén 1996). These cautions could include: the right to privacy, e.g. confidentiality; the right to full disclosure, e.g. the right to decline participation, risks and benefits; and informed consent. The cautions taken in papers I-IV will be discussed in the following text.

Paper I involves no directly contact with human subjects. The ethical considerations in this paper were to be true to the aim of the meta-analysis, and to include all relevant data from the original reports. Therefore, we have striven to handle the data so that it remains true to its sources by using evidentiary quotations from all the reports to verify the themes. All original reports are published in peer-reviewed journals and are available for those interested in checking the original data. Eleven out of 13 reports state that they have ethical approval from local ethic committees.

In papers II and III, a core principle of research ethics was the participants' possibility to give their informed consent. Therefore, in order to make a rational decision about participating, the potential participants had to be fully informed about the aim and procedure of the research as well as its potential risks and benefits (cf. Polit & Beck 2004). At the time of the interview confirmation was made that the participants in papers II and III had received the written information and that they were aware of the aim of the study, that participation was voluntary, that they could withdraw at any time without any explanations or consequences, and finally, that their privacy would be protected by not revealing their names or other identifiable features when reporting the findings, as recommended by Hermerén (1996).

The surgeon in charge of patients' medical care identified potential patients for interviews in paper II. To protect their and their family members' identity, only I had access to the list of patients and family members participating. None of the surgeons (DS, EN) who are co-authors in paper II and III have had access to participants' names or have read the transcripts of the interviews.

A central ethical consideration in paper II and III was that patients and their family members in general were in a vulnerable situation. To take up their time when many of them were going through a difficult period might be seen as an intrusion. Qualitative interviews may be considered intrusive as people interviewed lay open thoughts, feelings, and experiences which they perhaps did not want to share in the first place (Patton 2002). Although the participants were encouraged to speak freely, they were not pressed to talk about matters that they were reluctant to discuss (cf. Ternulf Nyhlin 1990). Each interview was carried out with sensitivity to their needs and abilities. Both patients and family members were sometimes emotionally touched during the interviews, and several of the patients were physically affected. However, no negative responses were expressed at that time or later. During the data collection

period, I had the opportunity to contact a physician or social worker and offering the participant a consultation with either of them.

In paper IV, participants received written information about the aim and procedure of the study. Health-care professionals were given the questionnaire by the head-nurse or another nurse at the clinic. The patients and their family members were first informed verbally, and to those who consented the questionnaire and written information were given by a nurse or a surgeon. All participants were informed that they were free to decline participation at any time, as not only interviews, but also questionnaire may be intrusive. This was shown in one case where a daughter wrote to say that her father had become worried after reading the items in his questionnaire. Since her father personally had not expressed this concern, it was deemed inappropriate to contact him at first. Instead, I wrote a letter to the daughter offering a meeting with the surgeon, a social worker, or me. She did not respond to that letter, which was interpreted that a meeting was not found to be necessary by her.

Furthermore, name registers, tape recordings, completed questionnaires, and transcriptions of interviews are kept so that no outsider could have access, which is advised by Hermerén (1996). All participants in papers II-IV gave their informed consent to take part in the studies. The research was granted formal approval by the Karolinska Institutet Ethic's Committee North (No. 00-303).

MAIN FINDINGS

Paper I

The aim of paper I was to extend knowledge about patients' and family members' experiences of living with oesophageal cancer, other upper gastrointestinal cancer, and head and neck cancer. Three themes were developed as a result of the thematic analysis, namely: *Running into an unpredictable enemy*, *Enduring a fading body*, and *Entering social silence*.

The first theme illustrates how receiving a diagnosis of cancer precipitates a crisis, as patients and family members are confronted with an unpredictable enemy. They experience that they are given a sentence of death and their certainty about health and life is deprived. Losing their perceived future is profoundly stressful for the whole family, including the children. Patients and family members live with daily apprehension of deterioration or a recurrence of cancer, which leaves them physically and mentally exhausted.

The second theme illustrates how patients suffer from a fading body, arising from threatening, complex, severe symptoms, and side effects of treatment. They have to adapt to physical restrictions that make them feel overwhelmed and imprisoned by the disease. These physical restrictions dominate the patients and change their ordinary daily lives. Changes in physical functions and appearance cause the patients to feel alienated from their own bodies and they feel they are not the person they used to be. Family members are eyewitnesses to how the patient's body fade, and they suffer from the patient's distress.

The third theme illustrates how the illness disrupts patients' and family members' social world and relationships and how the illness forces them to enter a social silence. The illness restricts their routines and family life and they become tied to their homes. Both intimate relationships and social contacts within and outside the family are broken and they feel abandoned and lonely. Patients experience social awkwardness and a self-induced withdrawal from social interactions, a process that is triggered by their feelings of embarrassment, disgust, and shame because of symptoms and side effects. The perceived absence of health-care professionals after discharge from hospital gave grounds for feelings of powerlessness, loneliness, and abandonment in patients and family members.

Paper II

Paper II addressed patients' experiences of living with oesophageal cancer. The findings are described in four categories: *Experiences of becoming a patient diagnosed with oesophageal cancer*, *Experiences of undergoing investigations and treatment*, *Experiences of intrusions in daily life*, and *Managing a life-threatening illness*.

Patients mostly felt healthy with minor and vague symptoms at the time of consulting their general practitioner. A delay in diagnosis was reported as inefficient management due to the general practitioner. 'The silence of the illness' meant that patients had no premonitions of the outcome of the initial investigations. They were unprepared and without knowledge of oesophageal cancer. After receiving the diagnosis, patients became aware of the seriousness of the situation raising questions about life and death.

The exhausting investigations and decision-making the patients went through caused them extreme and overwhelming tiredness. The illness with its symptoms and treatment, and uncertainty of the future affected patients' ordinary daily-life activities and roles and relationships between partners. Because of the immense difficulties in eating, patients lost the pleasure associated with eating. Patients experienced that their partners were more psychologically affected than they themselves were. Also, the children's lives were affected because of the gravity of their parent's illness. They were in need of information about the parent's illness adjusted to their own age and intellectual capacity. Patients emphasised a family perspective in nursing care. The everyday uncertainty about the future was profoundly stressful for the patients.

In order to manage their life-threatening illness, patients employed a variety of strategies. The predominant strategy was subordinating themselves to medical experts. Patients had faith in their physicians having the best knowledge. However, patients experienced that there were difficulties in continuity with physicians and they were afraid of taking up physician's time. Therefore, nurses were important sources for informational, practical, and emotional support. Another strategy was seeking information among family and friends who had medical knowledge and understood the patient's capacity to learn and understand. Exchanging experiences with fellow patients was found to be valuable to get a better understanding about the illness as their knowledge is based on personal experiences.

Some of the patients used the Internet to search mainly for facts about the prognosis of the illness. The information found was sometimes perceived unreliable or irrelevant. Patients often discussed information found on the Internet with the physician, and patients understood that this information was not always current and could not be applied to them. Some patients avoided seeking information due to fear of unwanted facts. In addition, weakness and fatigue caused by the extensive treatment and its side effects made them avoid additional information.

Paper III

In paper III, the aim was to describe family members' experiences, information needs, and information seeking in relation to living with a patient with oesophageal cancer. The findings are presented in four themes: *Experiences of receiving the diagnosis of patients with oesophageal cancer*, *Intrusions on family*, *Uncertainty*, and *Managing uncertainty*.

Family members expressed that due to vague symptoms of oesophageal cancer and lack of awareness of the disease, there was a patient's delay in presenting the physician with the symptoms as well as a doctor's delay in receiving the diagnosis. Family members went in a short time from ignorance of the disease to awareness of the seriousness of the diagnosis. So, when faced with this awareness, shock, stress, and disbelief were evoked in them. They expressed that the distress of the diagnosis was more apparent for them than for the patients. Family members felt that health-care professionals ignored them and that their emotional needs were neglected.

The cancer illness became intrusive into family members' everyday lives, routines, and life plans. The importance of including the whole family in the care, even the children, was emphasised. The children were faced with significant psychological stress, and had to struggle much on their own.

Uncertainty, involving the course and prognosis of the disease, was the main source of distress among the family members. The uncertainty of death and dying pervaded the family members' thoughts and plans for the future.

In order to learn, to gain understanding of the illness, and to manage the uncertainty, the family members as the patients, entrusted themselves to the experts and also sought information from them. However, family members did not always turn to the experts with questions because they experienced it difficult to formulate questions due to their lack of medical knowledge about oesophageal cancer. Not asking meant that they were denied knowledge that perhaps would have been of value for understanding the situation. Family members had a need to consult the physician without the patient being present since they did not want to discuss and ask difficult questions with the patient listening.

Other central sources for appropriate informational support were social network and kinship. Most of the family members used the Internet to obtain an overview about the illness and above all about the prognosis of oesophageal cancer. When they found out about the poor survival rates, they became shocked and worried. They discussed the information found face-to-face with the physician. This discussion was encouraging since they understood that information on the Internet was general and not tailored to their specific situation.

Paper IV

The aim of paper IV was to describe patients' and family members' information needs following a diagnosis of oesophageal cancer, their satisfaction with information obtained, and health-care professionals' perceptions concerning patients' and family members' information needs. This paper is a pilot study, and it shows that patients' and family members' need for information after a diagnosis of oesophageal cancer is substantial and has not been adequately met by health-care professionals. The mean value shows that there is low variation in the need for information among the different items. The mean value and rating for all items with regard to importance of information is presented in the appendix in the thesis.

Certain areas of information were considered more important than others. Both patients and family members consider information about tests/treatment and self-care to be the most important areas of information. Therefore, it appears that health-care professionals should concentrate on giving this type of information. Family members attached the highest importance to information about how the illness may affect the patient's life over time. Interestingly, the findings indicate that family members have greater informational needs than patients. In half of the items health-care professionals overestimated patients' needs for information and in half of the items underestimated their needs. In general health-care professionals underestimated family members' needs for information. We also found that both patients and family members considered information about what help and support a physician could assist them with to be of high importance. Physicians considered this to be one of the most important information needs for patients but of lower importance for family members.

Furthermore, it was found that patients and family members were only partly satisfied with information received.

METHODOLOGICAL REFLECTIONS

All research findings should be as trustworthy as possible. Therefore, the process of ensuring trustworthiness, for instance credibility and transferability, has continued throughout the whole research process (Graneheim & Lundman 2004, Meadows & Morse 2001). In papers I-IV, we have striven to describe the research process thoroughly and when presenting the findings of papers I-III, representative quotations from all original reports (paper I) and from the transcribed text (papers II, III) have been used.

Paper I

The research team

A meta-analysis involves steps similar to any other research project by articulating aims, research questions, and determining appropriate data collection and data analysis, but differentiates from other research projects in its inherent dependence on a team effort (Paterson *et al.* 2001). A major challenge associated with being a member of our team was that it was time-consuming because of the need to communicate and negotiate throughout the research process.

Having too many team members may be just as problematic as having too few. If the team is too large, effective communication can be cumbersome and collaboration about significant decisions may become difficult (Paterson *et al.* 2001). Our team consisted of four team members; a number we found constructive since it allowed effective communication and collaboration about significant decisions that needed to be taken. We invited a fourth member, with whom we had not worked previously, because of the importance of seeing things with fresh eyes. We believe this enhanced creativity because of our different pre-understandings and research experiences, leading to richer findings (cf. Schreiber *et al.* 1997).

Sampling and data collection

We decided that only peer-reviewed published reports should be included. This was due to the fact that unpublished material, for instance grey-literature, were problematical to access because they are not available in computerised reference databases. An additional reason was that the publication process in scientific journals is aimed at guarantying quality of the research reports.

Paterson *et al.* (2001) stress that it might not be possible to locate all research within a field of study. As Shaw *et al.* (2004) has reported, it was a challenge to find original qualitative reports since thesaurus terms used in reference database indexing systems are not designed specifically to identify qualitative research. Further, not having a structured question as a basis for deriving search terms made the search somewhat complicated. However, by initially testing many different search terms, the final terms were considered the most productive set – the set that enabled me to find

most of the eligible reports. The original reports included in this paper were published between 1998-2006.

It is difficult to specify the number of reports that should be included in a meta-analysis in order to make the project meaningful. Finfgeld (2003) and Paterson *et al.* (2001) stress that the number is dependent on the breadth of the topic, the state of the art of the topic, and the amount of data available in each report. Paterson *et al.* (2001) recommend an arbitrary number of twelve reports, which harmonises with the amount of paper I. However, a significant limitation is that only one original report focused solely on family members (Andreassen *et al.* 2005) and four reports on both patients and family members (Edwards 1998, Jones 2001, Richardson *et al.* 2002, Yi & Kahn 2004). Most of the reports were conducted in Sweden and in the United Kingdom (see Table 1 in paper I). The reports included do not reflect all aspects of living with oesophageal cancer, other upper gastrointestinal cancer, or head and neck cancer, for instance none of them focused on the palliative phase of cancer.

We have included a range of methodological approaches to cover our interest in the illness experiences that were reported in the studies. By including a diversity of context and methods, where these experiences were clearly expressed in the form of quotations and narratives, we believe we have gained a rich and multifaceted understanding.

Thematic analysis

Three of the team members analysed the reports. As Patton (2002) recommends, each of us identified key phrases, coded them, and classified them independently. This could be seen as a form of increasing trustworthiness. This process went smoothly with a great deal of agreement between the team members. Notwithstanding the harmony of our coding and classifications, there were small differences. I therefore compared all members' key phrases, codes, and classifications and created a tentative joint classification system. This system was discussed back and forth in the team until consensus was reached. We brought together the codes into categories engaging existential/psychological, physical, and social experiences and wrote a descriptive presentation of the findings.

The most time-consuming part of the analysis process has been to come up with a creative label of the themes, since this involved seeking explanations other than our first ideas and thoughts, as well as ensuring that variation and important details were not lost, and that the themes were not just a simplification of the findings. Throughout the entire analysis process we had frank, vivid, and creative discussions that allowed us to finally agree upon a mutual analysis.

By including only peer-reviewed published reports, the original findings are available for reference for any reader who wishes to check the original findings and their context. To verify our interpretations, we use evidentiary quotations from all reports when presenting the findings, as advised by Finfgeld (2003).

Papers II and III

Persons in the studies

In order to achieve as broad and varied descriptions as possible of the illness experiences, the patients in paper II had various ages, gender, and had undergone various treatment modalities for oesophageal cancer.

Qualitative interviews

When interviewing, the interview guide was the base for the dialogue and it ascertained that all predetermined topics were covered. My role as an interviewer was to encourage the participants to openly speak about the topics asked and to follow up the stories told by them. This was done by listening attentively and asking probing questions. The interviews started with an open-ended question as this permitted the participants to talk freely about what they believed to be most significant in relation to their illness experiences. In looking back, it seems that the interviews with family members were to some extent focused on the patient's illness and not so much on the family member's own situation. This could be a result of a lack in interview technique or that the opening question in paper III might not have captured the family members' experiences.

To optimise the preconditions for the interviews, each interview was scheduled to meet the participants' wishes. Most of them chose to be interviewed in their private homes. By carrying out the interviews in their homes a relaxed and undisturbed atmosphere was created, which facilitated the interview process. A few interviews were temporarily interrupted by telephone calls. One interview with a patient was held at a café. We sat in a secluded place, but during the interview we were disturbed on one occasion. When analysing the interview transcript, I understood that valuable information was lost because I missed asking probing questions due to this interruption. This could have influenced the nuances of the findings. At the time of analysis some time had elapsed since the interview and it was judged too late to come back to him on that subject.

The patient's illness contributed to an altogether unique interview situation. Patients were in different phases of the disease, where several of them were in an active period of treatment and were troubled with side effects such as pain and tiredness during interviewing. In this connection, I had strength from my clinical work as a nurse from which I had experiences in judging reactions and could carry out the interviewing with sensitivity to their needs and abilities.

To fulfil ethically acceptable conditions as well as preconditions for reliable data collection, it was necessary that sufficient time be allotted for each interview situation. Despite the fact that two successive interviews were carried out in one day, there was no stress and each participant was given as much time as he or she needed. Time was given for emotional reactions, and I was observant of signals that could indicate that the interview was too demanding. Even when the participants were physically troubled during the interview, none of them wanted to end the interview prematurely.

While most of the participants provided detailed accounts of their experiences, there were two participants who did not. Despite probing questions, the interviews lasted only approximately twenty minutes. The participants feeling uncomfortable, or individual differences in capacity to express oneself verbally, could be possible explanations. The interviews sometimes lacked enough depth, but in general, they provided insightful accounts of patients' and family members' experiences.

In rounding off the interviews, several of the participants explicitly told that they had wanted to participate to increase knowledge about the illness so that others would benefit, a result shown by Friedrichsen (2002) and Mattiasson (1995). Qualitative interviews have been shown by Lowes and Paul (2006) and McIlfatrick *et al.* (2006) to have a positive effect on patients.

Qualitative content analysis

Table 2 in paper II and text on pages 19 in this thesis give some examples of how text units, coding, and abstractions have been created since a critical issue for achieving credibility is how to select text units. Too narrow units may result in fragmentation and too broad units could contain various meanings (Graneheim & Lundman 2004). In papers II and III, these units were either a part of a sentence, a simple sentence, or several sentences bound together by their content.

The credibility of our research findings dealt with how well the categories in papers II and III, or the themes in paper I represented the data collected and how the similarities within and differences between categories were judged. One way of approaching this was to use quotations (cf. Sandelowski 1994), why representative quotations from the transcribed interviews were used to illustrate the illness experiences of patients and family members. Another way of achieving credibility was to seek agreement among co-researchers. However, validation among co-researchers is questionable, according to Sandelowski (1993), because the multiple realities that exist are dependent on subjective interpretations. Further, Meadows and Morse (2001) argue that the coding process must be based on the knowledge of the whole, and it is therefore unlikely that two coders will proceed in the same way, because a second coder may not have the same intimate knowledge of the interviews or time to reflect on them as the main researcher. Patton (2002), on the other hand, discusses that it is helpful to have multiple persons analysing the same data set. By means of this, important insights can emerge. In papers II and III, I conducted the processes of reading, re-reading, coding, and the preliminary categorisation. Two of the co-authors read all transcribed interviews and had access to the entire coding and categorisation process in order to achieve trustworthiness. We discussed my preliminary categorisation, which was found to be reasonable, and further classified data into main categories, categories, and sub-categories.

Trustworthiness in the present case included the question of transferability, which in turn referred to the probability that the findings had meaning and could be transferred to others in similar context and situations. Lincoln & Guba (1985) labelled transferability 'fittingness' which refers to the degree of congruence between two

contexts. If a context or situation is congruent to the context of papers II and III, the results from these two papers may be applicable for other patients with oesophageal cancer and their family members. However, determining whether the findings are transferable to another context rests with the potential users of the findings (Johnson 1997, Sandelowski 1986).

Paper IV

Study specific questionnaire

One major limitation in paper IV is that the questionnaire has not been tested for reliability. Reliability is a statistical measure of the stability of an instrument, of its consistency, and how reproducible the survey instrument's data are (Streiner & Norman 2003).

The stability of a questionnaire refers to the extent to which the same result is obtained on repeated administrations of the questionnaire. The less variation an instrument produces in repeated measurements, the higher its reliability. Reliability could be tested by administering the same questionnaire to a target sample on two occasions and then compare the scores obtained, i.e. test-retest reliability (Streiner & Norman 2003). This has not been done because information needs do change over time. If patients or family members had received additional information between the two administrations of the questionnaire, the measures would not yield consistent scores at the two separate occasions. Another reason for not performing test-retest was due to patients' and family members' vulnerable situation. If they had found answering the questionnaire tiresome on the first occasion, then they might have responded randomly at the second occasion, resulting in a spuriously low estimate of stability. Not having tested the questionnaire for stability means that we cannot claim that the questionnaire produce scores that are internally consistent or stable across time, in the same group of participants, or in the same individual participant. Another aspect of reliability is how well items in a subscale measure the same issue, i.e. internal consistency or homogeneity (Litwin 1995). We can not claim that the items within the subscale measure the same attribute. What could be said is that the questionnaire as a whole, and the items within each subscale, is a collection of items that fit well together.

Validity refers in general to the degree to which a questionnaire measure what it is supposed to measure (American Educational Research Association *et al.* 1999). Traditionally it is common to speak about different types of validity. The three most common are: content, criterion, and construct validity. Content validity concerns the degree to which the items in a questionnaire are an appropriate sample for measuring the concept (Streiner & Norman 2003). This form of validity is not quantified with statistics, rather, it is presented as an overall opinion of a group of trained judges (Litwin 1995). To ensure content validity, several steps were undertaken: a thorough review of the scientific literature in the area was made, qualitative interviews were carried out, as well as consultations with clinical experts in surgery and surgical nursing contributed to developing the content of the questionnaire (cf. American

Educational Research Association *et al.* 1999, Shea & Fortna 2002). The content validity of this questionnaire was based on the subjective opinion and judgment of these clinical experts as to what they considered appropriate, representative, and important items about information needs in oesophageal cancer.

Sample and data collection

Achieving quality in research demands a high response rate. The total response rate for health-care professionals was 85 %. However, there have been major problems with data collection from patients and family members. At first it was difficult to recruit patients in three clinics with an ongoing reorganisation in one of them. I believe that if I had been more personally involved in the data collection processes, it would have been easier to control the process, leading to a higher response rate and thus achieving higher quality. Due to the reorganisation in one unit it was difficult to determine the exact number of questionnaires that had been distributed to patients and family members. We know for sure that approximately 40 patients and 40 family members had been given the questionnaire. Of these 15 patients (38 % response rate) and 16 family members (40 % response rate), fulfilled participation criteria and returned the questionnaire. Non-participation is a potential source of selection bias. It is possible that patients and family members who chose not to participate in this study could have had different information needs, compared to those participating, e.g. a different stage of the illness.

The patients' received their diagnosis shortly before filling in the questionnaire. Therefore, patients and family members could have been in a state of shock that made it difficult to recall the information provided to them. This might have influenced the result, therefore, we may have not fully captured their actual needs of information.

Further, patients started treatment a short time after receiving the questionnaire, which may have made it problematic to fill in the form within two weeks. The response rate might have been different if the participants had been given the possibility to fill in the questionnaire at the hospital directly after receiving it. In general it is convenient and efficient to fill in questionnaires in the clinical setting (Polit & Beck 2004). We wanted to give the participants opportunity to complete the questionnaire in their own homes where it could be done in privacy without any feeling of stress. Out of consideration for the nature of the illness, only one reminder was sent. When participants received the reminder, patients could be in hospital receiving surgical or oncological treatment and for understandable reasons did not prioritise participation. Moreover, written comments revealed that participants found the 64 items questionnaire too extensive. Those that were returned were generally thorough and complete.

Statistical analysis

A non-parametric test (Svensson 1998) was performed on some items where the variation in patients' and family members' ratings appeared significant. This test was found suitable since it measures the systematic differences between paired groups.

Individual items with response options such as *not important* to *very important* are considered ordinal scales (Di Iorio 2005). By calculating the arithmetic mean, we had the possibility to rank the items and compare the importance of the various items between the subject groups. According to Di Iorio (2005), it is a common practice for researchers to apply parametric statistics, in our case arithmetic mean, to the study of variables that are measured with ordinal scales. Asking patients to rate satisfaction with information received has potential problems such as patients not wanting to seem ungrateful and therefore rate satisfaction as high, and patients grasping for information and therefore view everything they are given as good. Patients' and family members' satisfaction with information has been reported on a subscale level (see Table 4 in paper IV). This is problematic because we do not know for sure if the different items composing the subscale are measuring the same issue. Another problem is that a single item could be rated very high and the remaining items low, resulting in a high overall mean value for that specific subscale.

The items in the questionnaires were rated on a four point Likert scale. A limitation with Likert scales is that they could produce a 'ceiling effect' in which the majority of the items are rated high, described by Wen and Gustafson (2004). The descriptive statistical analysis shows that both patients and family members considered most of the informational items in the questionnaire to be of high importance. The high rating of items by all subject groups could be explained by this 'ceiling effect'. This means that there is a low variability among the rated needs, giving us little guidance as to where to concentrate the information giving. However, we know from qualitative interviews (Andreassen *et al.* 2005, 2006, Mills & Sullivan 2000) that patients with oesophageal cancer and their family members have substantial needs for information.

All together, these limitations make it difficult to draw any general conclusions from the findings. Notwithstanding these limitations, paper IV provides valuable information and meaningful insight into the importance of information for patients and family members following a diagnosis of oesophageal cancer.

REFLECTIONS OF FINDINGS

From ordinary daily life to living with a life-threatening illness

As oesophageal cancer was experienced as coming without warning, patients and family members in papers II and III experienced that the patients suddenly went from being healthy to being a patient with a life-threatening illness. Both patients and their family members were unprepared for receiving the diagnosis of a life-threatening illness and they were without knowledge of what the illness entails. The diagnosis became a threat to the entire family. As reported by Houldin and Lewis (2006), it is not uncommon that patients feel unprepared for different aspects of the cancer experience. The unanticipated and sudden change put the family (papers I-III) in a state of crisis, which had consequences both for the patients who were affected and for their families. Uncertainty about the illness, its progress, and eventual deterioration posed a major distress. The participants experienced an overwhelmingly stressful uncertainty because of the loss of health and their perceived future, also reported by Shaha and Cox (2003) and Wideheim *et al.* (2002).

In papers I-III, existential concerns and questions about life and death were raised when patients and family members finally became aware of the illness. There was a delay in diagnosing (papers II and III). One explanation for this delay was the unawareness of the seriousness of the symptoms. Rothwell *et al.* (1997) and Irving *et al.* (2002) discuss that further explanations could be the family doctor's delay in referring the patient to a specialist and in establishing the correct diagnosis. Leydon *et al.* (2003) stress that delay in diagnosis triggers feelings of disappointment in patients and family members because they feel they cannot trust the physicians.

Patients and family members in paper I experienced distress and suffering which had a clear physical foundation: the symptoms of cancer and the side effects of treatment. Symptoms has been reported by Houldin and Lewis (2006) to represent more than merely the physical symptoms. They represent losses such as loss of weight and loss of energy. However, the patients' distress and suffering in paper I extended beyond these physical manifestations involving both emotional and social life. In papers I-III, family members experienced more psychological distress than the patients, earlier reported by Ferrell *et al.* (2002). They emphasise that this distress could stem from family members' lack of control and feelings of helplessness.

Falling ill with oesophageal cancer lead to major changes in life and routines for patients and family members in papers I-III. The illness intruded upon the whole family and restricted their routines, range of activities, and life plans. Ordinary daily activities became an uphill struggle for the patients in papers I and II due to extreme tiredness/fatigue. This fatigue was experienced as one of the most troubling symptoms because of its interference with the ability to function at their normal capacity. According to Quinn and Reedy (1999) and Verschuur *et al.* (2006) fatigue is experienced as one of the most problematic symptoms in patients with cancer because of its negative impact on their efforts to resume or perform social activities. So,

patients' fatigue will have an effect on the whole family. This was also seen among family members in paper I, who expressed that they were physically drained because of the practical and emotional impact the illness had on them. Plant (2001) discusses that this drain might be attributed to the patient's fatigue which forces family members to take on additional chores or practical tasks. Wideheim *et al.* (2002) highlight that the patient's illness and lack of energy may also increase the burden for family members. Additionally, Kirkevold (2003) stresses that chronic illnesses and cancer leads to physical and mental tiredness, and seriously restrictions of family members' freedom.

In papers I-III, dysphagia was described as a distressing symptom, which caused difficulties in eating and drinking. Not being able to share mealtimes together as a family precipitated isolation, a sense of exclusion, and distress at meal times. This might be because eating together is regarded as a symbol of life being inescapably social and communal (cf. Bailey 2004). As the disease progressed, eating and drinking became time consuming and required substantial physical effort. Dysphagia and side effects of treatment triggered changes in the patients' dietary habits, and subsequently lead in part to changes in the family's dietary habits. This is in line with Watt and Whyte (2003) who report that dysphagia interfered with patients social activities, and consequently with family life.

It was found in paper I that the illness caused social isolation. There were many reasons for the isolation, such as stigmatisation, deficient support, troubling symptoms, decrease in functions, and medical aids such as percutaneous enteral gastrostomy (PEG) as an obstacle for social participation. Kirkevold (2003) report that social isolation in patients with chronic illnesses is not uncommon. Further, Ferrell *et al.* (2002) stress that patients with cancer often choose isolation because they feel 'different' and feel that they do not fit in among the 'normal' population. This is in accordance with findings from paper I where patients withdrew from social interactions due to social awkwardness because of physical discomforts. This, as well as the failure of health-care professionals to address patients' and family members' unique needs, caused feelings of abandonment and loneliness. Kirkevold (2003) discusses that healthy and ill people live in different spheres in the society with different perceptions of reality and routines. They are no longer able to take part in activities they earlier devoted time to; working life, school, leisure activities, and different social activities.

In papers I-III it was further expressed that most attention from health-care professionals was directed towards the patients, and the needs of the family member came in second place. This made family members feel neglected and invisible in contact with health-care services. It was obvious that family members did not articulate their own needs. Family members have a tendency to set aside their own needs, and health-care professionals seldom ask family members directly how they feel or if the staff can help them. According to Ferrell *et al.* (2002), family members are hesitant to express their own needs given the serious health problems of their ill family member.

Family members in papers I and III missed being an active member and being seen and heard. Lewis (2006) stresses that social support is a key factor in an individual's ability to cope with a threatening situation, such as cancer. The inability to engage in normal social activities could mean a reduction in that source of support.

Most patients diagnosed with oesophageal cancer are men over 70 years (The National Board of Health and Welfare 2006). However, several of the participants in papers II and III were younger and had children of school age. The findings elucidate that the parents' illness had an effect on the children's lives by influencing their schoolwork and daily life. Lewis (2006) highlights that this kind of distress relates among other things to the threat to the child's sense of security. Participants in papers II and III called attention to the need of involving the children in their parent's illness. Parents need, according to Kroll *et al.* (1998), support from health-care professionals about how to deal with their children's feelings, reactions, and questions.

What patients and family members need to know and ways of seeking information

The need to know

Based on results from paper IV, it is difficult to specify which information patients and family members were the most in need of. Their information needs were overall high and there was a low variability among the rated needs. This gives little guidance as to where to concentrate the information giving. Findings from papers II and III indicate that patients and family members most of all had a need for information about diagnosis, treatment, side effects, and prognosis. Family members in particular wanted information about the prognosis. Prognosis statistics are, however, always based on a large population, why patients and family members ought to be invited to discuss the individual patient's prognosis with health-care professionals.

As reported in paper IV, health-care professionals had not satisfactorily met patients' and family members' needs for information. The reason could be that they received information they perceived as not relevant, and on the other hand missed certain information which is supported by Champman and Rush (2003). These authors report that one reason for patients and family members being dissatisfied with cancer-related information is that the information is not individualised to their specific situations and cancer types. Further, Fitch (2005) suggests that one reason could be that patients do not understand the language of health-care. Having an illness could be described like entering an unfamiliar world filled with a great deal of new language, and patients may have difficulties accessing pertinent information in everyday language. Family members in paper III felt left out because they thought they lacked sufficient medical knowledge in order to pose relevant questions. Manning and Dickens (2006) discuss that many patients feel embarrassed or reluctant to ask physicians or nurses for information because they do not want to expose their lack of understanding.

Results in paper IV indicate that family members had higher informational needs than patients. This could be referred to findings from papers I-III, which highlight

that family members tended to be more anxious and psychologically affected following the diagnosis of oesophageal cancer than patients. Fitch (2005) states that patients living with advanced disease have high information needs because they want to understand what is happening to them and to their bodies. Further, information enables them to participate in decision-making. Both patients and family members may feel better prepared for what will happen if they know about anticipated bodily changes and what they might expect to feel and see. Family members in paper III used information seeking as a strategy to handle their uncertainty. In line with Houldin and Lewis (2006), information might help to create a realistic expectation about the typical course which might help to release this uncertainty.

Ways of seeking information

Participants in papers II and III actively sought information about the disease, prognosis, and different aspects of the illness. Channels for information seeking included interpersonal sources and interactions with health-care providers, social networks, friends and family, and mass media sources, e.g. television, Internet websites, and self-help books.

The most actively used mass media source was the Internet, which was used mainly to seek general information about oesophageal cancer and especially about the prognosis. Norum *et al.* (2003) and Ziebland *et al.* (2004) found that patients used the Internet to interpret symptoms, seek information about tests and treatments, identify questions for doctors, make anonymous private inquiries, and raise awareness of the cancer. Patients and family members (II and III) felt shocked and distressed when they found information about the poor survival rate.

Also older participants in papers II and III were familiar with computers and sought information on the Internet. Encouragingly, they discussed the information face-to-face with the physician, and thereby came to the understanding that the information on the Internet was not always reliable or relevant since the information was general and not tailored to their specific situation. This finding points out the significance of health-care professionals assessing patients' and family members' information needs, and the finding brings out the value of having someone in the health-care system to discuss information with. One reason why patients and family members (papers II and III) went to media sources for information might be, as discussed by Brashers *et al.* (2002) that these sources were convenient to use and allow anonymous or private use. Family members (paper III) found it difficult to ask questions since they felt that they did not have sufficient knowledge in order to formulate the question. Patients (paper II) were sometimes afraid of bothering the physician. Media sources were therefore expressed as convenient and allowed the participants to get an overview over illness-related questions, without exposing their perceived ignorance.

Notwithstanding the Internet as a growing source of information, it did not overcome the value of human encounters. Interpersonal sources were therefore expressed in papers II and III to be the most significant mode of information. The

primary source of information was the physician. Family members in paper III expressed the need to consult the physician without the patient being present since they did not want to discuss and ask difficult questions with the patient listening. Wideheim *et al.* (2002) explain that this could reflect that the family members considered it unnecessary that the patient should receive information about things that might happen. This was because family members believed it was important to retain hope. Forcing information upon patients could thus deprive them of their hope. In paper IV, most often patients and family members wanted information together with other family members and not alone.

Nurses were other valuable sources of information for the participants in papers II and III, due to their strategic role in the team caring for these patients. Both patients and family members expressed that nurses provided practical and emotional support in addition to informational support.

Follow-up information as well as having a person to contact continuously after discharge from hospital was considered central for both patients and family members (paper IV). This person could be a specialist nurse, which was requested by patients in a study by Mills and Sullivan (2000). Viklund *et al.* (2006a) report that information given by a specialist nurse for patients with oesophageal cancer is easier to understand for patients compared to information provided by the physician. However, the authors found that patients considered information given by the physicians to be more important than given by the specialist nurse. Despite the significance of the physician, participants in papers II and III sometimes did not turn to him/her with questions because they did not want to take up the physician's valuable time. The interpersonal contact was possibly invaluable not only for the more 'technical' support provided but also the social support they provided, also reported by Brashers *et al.* (2002) and Johnson and Meischke (1991).

Further valuable interpersonal sources, reported in papers II and III, were found to be family and friends with medical knowledge, because they understood the patient's capacity to learn and understand and that family members' felt confidence in them. The patient himself was often a significant source of information for family members.

As reported in papers II and III, exchanging experiences with fellow patients or people similarly afflicted could provide a better understanding about the illness and the future. The rationale for this was that fellow patients' knowledge was based on personal experiences, they used everyday language, and were aware of what information was needed. According to Fitch (2005), cancer patients value informational support from fellow patients because they are experts on the illness and facilitate low risk discussion on high risk topics.

Finally, this thesis contributes to the understanding of patient's and family members' needs when confronted with a devastating illness. This understanding is relevant for health-care professionals in general and especially for nurses. In the care of patients with a life-threatening illness it is necessary to have a professional presence and yet

be open and supportive in listening to both patients' and family members' experiences. The expression of authentic empathic understanding and attentive listening will help patients and family members to put their experiences into words. When understanding these particular family's needs, health-care professionals will then be able to respond accordingly.

Caring for these patients involves, apart from clinical assessment and management of side effects, education and support for the whole family. There is a need for continuity in contact with health-care personnel. A personal contact nurse would have an important role in supporting and guiding these patients and family members. Moreover, the personal contact nurse could provide them with opportunities to discuss their experiences and concerns.

CONCLUSIONS

This thesis provides insights of:

- Receiving the diagnosis of oesophageal cancer is suddenly going from feeling healthy with vague symptoms to having a life-threatening illness.
- Living with oesophageal cancer and clinically similar cancer forms means going through three phases: Firstly, receiving a diagnosis of cancer precipitates a crisis. Secondly, patients suffer from a fading body, arising from threatening, complex, severe symptoms, and side effects of treatment. Thirdly, the illness disrupts patients' and family members' social worlds, and relationships.
- Patients' and family members' needs for information following a diagnosis of oesophageal cancer is overall high with little variability among the rated needs.
- Information should be tailored to patient's and family member's individual needs. For understanding and managing the illness, information sources included health-care professionals, social networks, and media sources.
- Family members experience feelings of neglect in contact with health-care services and patients feel abandoned and left on their own. The whole family is affected and faced with uncertainty when a person in the family is diagnosed with oesophageal cancer. This highlights the need for focusing on the whole family, including children.

FUTURE RESEARCH

As shown by this thesis, we need to understand the impact oesophageal cancer has on patients, their family members, and on their ordinary daily life. Further research from an insider perspective needs to be initiated and carried out to more fully understand the life situation from both the patient and family member perspective:

- how patients' and family members' experience living with oesophageal cancer in the late palliative phase
- patients' and family members' strategies in handling living with oesophageal cancer
- patients' and family members' experiences and coping behaviour of long-term survivorship

SVENSK SAMMANFATTNING (SWEDISH SUMMARY)

Livssituation, informationsbehov och informationssökning hos patienter med matstrupscancer och deras närstående

Cancer i matstrupen, där kardinalsymtomet utgörs av sväljningssvårigheter, är en av de snabbast ökande cancerformerna i västvärlden. Orsak till denna ökning är inte känd men tobaksrökning, hög alkoholkonsumtion, reflux och övervikt är kända riskfaktorer. Eftersom cancertumören kan växa sig stor innan den börjar ge besvär, får patienten oftast kliniska symtom först när cirka hälften av matstrupslumen är igentäppt av tumörvävnad. Detta gör att diagnos sker i långt framskridet skede, vilket medför att patienten vid diagnostillfället ofta har dottersvulster. Femårsöverlevnaden är endast fem till femton procent. Oavsett om behandlingen omfattar resektion av matstrupen, och/eller cellgifts-/strålbehandling krävs en lång återhämtningsfas då patienten måste hantera såväl den fysiska effekten av behandlingen såväl som den känslomässiga aspekten av att ha en livshotande sjukdom.

Hela familjen påverkas när en familjemedlem drabbas av något så svårt och genomgripande som en cancerdiagnos. Det innebär att man måste se till familjen som helhet och till de enskilda familjemedlemmarna för att förstå hur cancer i matstrupen påverkar en familjs livssituation.

Information i samband med en cancerdiagnos har visat sig ha stor betydelse både för patienter och för deras närstående. Den är viktig för att minska stress, lindra ångest och för att bättre förstå vad som är att vänta. Information bidrar vidare till en ökad känsla av kontroll. En väl informerad patient stärker sin ställning och möjlighet att delta i den egna vården. Patient och närstående uttrycker dock ofta en otillräcklighet och en otillfredsställelse med den information som de fått från hälso- och sjukvården.

Med tanke på den korta överlevnaden vid matstrupscancer är det angeläget att omhändertagandet i vården blir så optimalt som möjligt för såväl patient som närstående. En fördjupad förståelse för vad det innebär att leva med matstrupscancer, samt för patienters och närståendes behov av att lära om och förstå sjukdomen är en förutsättning för att på sikt förbättra vården och livssituationen för dem.

Mot bakgrund av ovanstående ingår i föreliggande avhandling följande fyra delarbeten:

Delarbete I är en kvalitativ metaanalys av publicerade originalartiklar med syfte att ur ett patient- och familjeperspektiv få en fördjupad kunskap om hur det är att leva med matstrups-, övre gastrointestinal- och huvud/halscancer. Dessa cancerformer är jämförbara så till vida att symtom, behandling, komplikationer och prognos är mycket likartade.

Arbetsprocessen i metaanalysen bestod i två delar: en systematisk litteratursökning för att identifiera artiklar, samt analys och tolkning av tidigare publicerade resultat. För att identifiera relevanta studier genomfördes en systematisk sökning i medicinska och omvårdnadsdatabaser, samt genom manuell sökning i böckers och artiklars referenslistor. Cirka 150 artiklar identifierades i databaserna. Efter granskning av titel, abstract eller hela artikeln, exkluderades artiklar med resultat som bearbetats kvantitativt; artiklar med blandade metoder där de kvalitativa resultaten inte kunde separeras från kvantitativa resultat; samt ledare och fallbeskrivningar. Slutligen återstod tretton kvalitativa artiklar från referegranskade omvårdnadstidskrifter, publicerade under perioden april 1998 och juni 2006.

Metaanalysen genomfördes av ett team bestående av mig och tre seniora forskare. En tematisk analys användes för att analysera resultaten från artiklarna. Genom en reflektiv och levande dialog formulerades tre teman: 'Att springa rakt mot en oberäknelig fiende', 'Att uthärda en kropp som försvagas' och 'Att träda in i en social tystnad'.

Temat 'Att springa rakt mot en oberäknelig fiende' beskriver patientens och närståendes upplevelse av hur livet plötsligt och oväntat förändras när de får diagnosen. De upplever att de får en dödsdom och den trygghet de kände inför sin hälsa och sitt liv frántas dem. Att förlora sin tänkta framtid upplevs som mycket påfrestande för hela familjen, inklusive barnen. Patienter och närstående lever med daglig oro och osäkerhet över sjukdomsutvecklingen och över framtiden, vilket bidrar till att det känns fysiskt och mentalt utmattade.

Temat 'Att uthärda en kropp som försvagas' beskriver patientens upplevelser av påtagliga och hotande fysiska symtom och biverkningar av olika behandlingar. De får anpassa sig till sina fysiska begränsningar som gör att de känner sig överväldigade och fångna av sjukdomen. Dessa fysiska begränsningar dominerar och förändrar deras dagliga liv. Förändringar i både fysisk funktion och utseende bidrar till att patienterna känner ett främlingskap inför sin egen kropp och de känner att den inre självbilden förändras. De närstående lider av att vara åskådare till att patientens kropp försvagas.

Temat 'Att träda in i en social tystnad' beskriver hur det dagliga livet för patienten och i viss mån närstående begränsas och blir bundet till hemmet. Utmattning hindrar patienten att genomföra de enklaste aktiviteter som att ta promenader, åka till stan och/eller att delta i sociala aktiviteter utanför hemmet. Olust och skamkänslor i samband med måltider påverkar samvaron med vänner och därmed också det sociala livet. Även det känslomässiga klimatet i familjen påverkas. Inte sällan uppstår konflikter i parrelationen. När de har frågor eller har behov av att prata om känslor, tankar och funderingar råder en osäkerhet om vart de skall vända sig. De känner sig övergivna av sjukvården.

Syftet med **delarbete II** var att beskriva patienters upplevelser av att leva med matstrupscancer och hur de söker information om sjukdomen. Kvalitativa intervjuer utfördes med patienter som genomgått resektion av matstrupen och/eller

strålbehandling i botande/palliativt syfte. Det insamlade materialet bearbetades utifrån en kvalitativ innehållsanalys. Av resultatet framgår att patienterna inte kände till sjukdomen matstrupscancer och att de på grund av vaga symtom, som ont i halsen och trötthet, var totalt oförberedda på diagnosen. Diagnosen upplevdes som ett dödshot och existentiella frågor och tankar om liv och död uttrycktes. Biverkningar av behandling, de progressiva sväljningssvårigheterna och den extrema tröttheten bidrog till att måltiderna blev tidskrävande och förvandlades från njutning till en kamp för överlevnad. De fick svårt att genomföra dagliga enkla aktiviteter. När patienterna sökte information om sjukdomen, såsom prognos och behandling, vände de sig till vänner och närstående med medicinsk kompetens samt till medpatienter. Dessutom använde de massmedia och till viss del Internet som källor till information.

Syftet med **delarbete III** var att beskriva närståendes upplevelser av att leva med en patient med matstrupscancer, och deras informationsbehov och informationssökning. Det insamlade materialet analyserades utifrån kvalitativ innehållsanalys. Av resultatet framgår att närstående var oförberedda på en cancerdiagnos och att diagnosen var okänd för dem. De blev chockade och den psykiska påfrestningen var stor. Vidare framgår att närstående levde i rädsla och osäkerhet beträffande sjukdomens utveckling och över framtiden. De upplevde att patientens sjukdom inskränkte på det sociala livet. Patientens svårigheter att äta påverkade familjesamhörigheten. Det framkom att barnen berördes starkt av föräldrarnas sjukdom vilket tog sig uttryck i att deras skolarbete blev lidande med lägre betyg som följd. För att hantera situationen och den osäkerhet och rädsla de närstående kände, sökte även de information om sjukdomen i massmedia, böcker, Internet och hos personliga kontakter. Den primära källan till information var patientens behandlande läkare. Några närstående hade en reserverad inställning till att söka information eftersom sökandet krävde tid, mod och energi.

Syftet med **delarbete IV** var att beskriva informationsbehovet hos patienter med matstrupscancer och deras närstående samt beskriva tillfredsställelsen med erhållen information. Vidare var syftet att beskriva personalens uppfattningar om patientens och närståendes förväntade informationsbehov. Ett frågeformulär utarbetades med 64 påståenden fördelade på följande områden: egenvård, psykosociala faktorer; sjukdomen; anatomi och fysiologi; utredning/undersökningar/behandling; informations metoder; samt information om hälso- och sjukvårdspersonals kompetens. Patienter, närstående, sjuksköterskor, undersköterskor och läkare besvarade frågeformuläret. Av resultatet framgår att det största behovet av information var relaterat till egenvård, nutrition och undersökning/behandling. Vidare visar resultaten att det förelåg en skillnad mellan patienters och närståendes behov av information, och mellan vad vårdpersonalen uppfattade som viktig information. Närstående tenderade att ha ett större behov av information än patienten. Därutöver framkom att patient och närstående var delvis missnöjda med informationsgivningen.

Slutsatser

Att diagnostiseras med cancer i matstrupen innebär att på kort tid gå från att känna sig frisk till att vara en patient med en livshotande sjukdom. Att leva med matstrupscancer och kliniskt likartade cancersjukdomar innebär att livet för patienten och familjen förändras plötsligt och oväntat. Patienten upplever påtagliga och hotande fysiska symtom och biverkningar som försvagar kroppen. Det dagliga livet för patienten och i viss mån närstående begränsas och de känner sig socialt isolerade.

Patienten och närstående har stora behov av information. För att hantera sjukdomen och den osäkerhet som sjukdomen medför söker de information från personer i deras närhet och massmedia.

Hela familjen påverkas och konfronteras med osäkerhet när en familjemedlem får diagnosen cancer i matstrupen. Närstående känner sig åsidosatta av sjukvården och patienten känner sig övergiven och lämnad åt sig själv. Sammanfattningsvis är det viktigt att integrera familjen i patientens vård och behandling och att erbjuda möjligheten till en personlig kontaktsjuksköterska som kan utgöra stöd för familjen

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APPENDIX

Item	It is important for me to know...	Patients (n=15)		HCP's perceptions of patients' needs (n=34)		Family members (n=16)		HCP's perceptions of family members' needs (n=34)	
		Rank	Mean	Rank	Mean	Rank	Mean	Rank	Mean
	<i>Tests/treatment</i>								
17	why I have/will have a gastrostomy in my stomach	26	3.5	1	3.87	33	3.64	9	3.7
18	how the tests/treatments are done	26	3.5	18	3.63	39	3.56	52	3.09
19	advantages and disadvantages of different treatment alternatives	3	3.77	15	3.69	18	3.84	15	3.61
20	how I will feel during the tests/treatments	13	3.64	33	3.53	35	3.63	30	3.45
21	how I will feel after the tests/treatments	5	3.71	34	3.5	7	3.88	34	3.42
22	why I have to undergo the different treatments	9	3.69	18	3.63	43	3.44	19	3.58
23	how to prepare for the different tests/treatments	20	3.57	28	3.56	35	3.63	45	3.27
24	which complications from treatment/tests that could occur	17	3.6	43	3.32	23	3.75	37	3.41
25	the possible side effects of the medicine	20	3.57	34	3.5	31	3.67	42	3.38
26	when and how I will get the results from tests/treatments	25	3.53	12	3.73	9	3.87	25	3.52
	<i>Health-care professionals competence</i>								
27	what help and support a dietician can assist me with	36	3.4	28	3.56	19	3.8	30	3.45
28	what help and support a registered nurse can assist me with	5	3.71	18	3.63	29	3.71	27	3.47
29	what help and support a physiotherapist can assist me with	53	3.11	55	3.07	41	3.55	55	2.91
30	what help and support an occupational therapist can assist me with	49	3.22	57	2.9	43	3.44	59	2.72
31	what help and support a physician can assist me with	1	3.86	15	3.69	2	3.93	15	3.61
32	which physician is medically responsible for me	5	3.71	4	3.81	9	3.87	3	3.76
33	the routines of the ward	43	3.31	54	3.13	49	3.38	53	3.03
	<i>Information methods</i>								
34	where I can search information on the Internet	55	2.89	62	2.5	57	3	63	2.38

Item	It is important for me to know...	Patients (n=15)		HCP's perceptions of patients' needs (n=34)		Family members (n=16)		HCP's perceptions of family members' needs (n=34)	
		Rank	Mean	Rank	Mean	Rank	Mean	Rank	Mean
35	receive information about my illness together with my family	35	3.43	9	3.78	23	3.75	2	3.79
36	receive information on my own about my illness	57	2.83	61	2.54	53	3.25	62	2.55
37	receive information by a video film	63	2	64	1.86	64	2.29	64	1.83
38	meet other people with the same illness that I have	63	2	63	2.4	63	2.3	60	2.61
39	have a book/booklet where I can read about oesophageal cancer	62	2.14	52	3.17	57	3	37	3.41
40	have follow-up information from the hospital after the investigation period has ended	13	3.64	17	3.67	4	3.92	37	3.41
41	have a person to contact continuously when I am in hospital and after discharge	26	3.5	13	3.71	22	3.77	7	3.74
	<i>Self-care</i>								
42	which household tasks I can do at home	49	3.22	58	2.88	56	3.15	58	2.75
43	if I will need help to take care of myself when I come home	10	3.67	37	3.42	37	3.62	48	3.26
44	what to do if I get problems with taking my medicine	17	3.6	26	3.59	2	3.93	14	3.65
45	how to care for the gastrostomy (peg)	26	3.5	1	3.87	23	3.75	1	3.85
46	what to do if there are problems with deliveries of enteral nutrition and tubes	58	2.8	24	3.61	6	3.91	21	3.56
47	how to know how many bottles of enteral nutrition I need	44	3.3	37	3.42	23	3.75	40	3.39
48	what to do if there is an obstruction in the gastrostomy	36	3.4	4	3.81	23	3.75	9	3.7
49	for how long I might need enteral nutrition	44	3.3	41	3.39	31	3.67	50	3.15
50	which food I can or cannot eat	8	3.7	18	3.63	13	3.86	33	3.44
51	who I should contact if I need help with enteral nutrition	42	3.33	3	3.84	17	3.83	15	3.61
52	how to handle problems with reduced appetite, vomiting and difficulty swallowing	10	3.67	11	3.75	4	3.92	27	3.47
53	how to choose food that help me to retain my weight	23	3.55	18	3.63	20	3.79	18	3.59
54	how to take care of myself	22	3.56	42	3.34	15	3.85	43	3.3

Item	It is important for me to know...	Patients (n=15)		HCP's perceptions of patients' needs (n=34)		Family members (n=16)		HCP's perceptions of family members' needs (n=34)	
		Rank	Mean	Rank	Mean	Rank	Mean	Rank	Mean
	<i>Psychosocial aspects</i>								
55	what emotional reactions are normal during a crisis, i.e. severe illness	56	3.75	49	3.25	52	3.29	25	3.52
56	where I can get help to deal with my fear, my thoughts and my feelings	26	3.5	28	3.56	46	3.43	9	3.7
57	where my family can go if they need help	2	3.82	40	3.41	42	3.5	12	3.69
58	what the hospital church can offer in the form of help and support	61	2.63	59	2.76	59	2.89	57	2.82
59	what to do if I have thoughts and questions about death	55	2.89	44	3.31	60	2.83	45	3.27
60	how to talk with my family about my illness	44	3.3	46	3.28	54	3.21	30	3.45
61	if it is possible to get financial help	40	3.36	53	3.19	39	3.56	51	3.12
62	how my family might react to my illness	17	3.6	50	3.16	55	3.18	34	3.42
63	who to contact if I have questions	10	3.67	4	3.81	15	3.85	3	3.76
64	what help and support a social worker can provide	47	3.25	26	3.59	49	3.38	21	3.56
	Total mean value for all items		3.35		3.41		3.54		3.35

The wordings of the items are according to the patient's questionnaire.