A meta-analysis of qualitative studies on living with oesophageal and clinically similar forms of cancer, seen from the perspective of patients and family members

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Abstract
This study is part of a research programme of which the aim is to generate knowledge about patients’ and family members’ experiences of living with oesophageal cancer from their perspective. The aim of the present study was to extend this knowledge by adding other forms of cancer: other upper gastrointestinal cancer, and head and neck cancer. These cancer forms have clinical similarities with oesophageal cancer and the survival rates are similar. This study is a qualitative meta-analysis that examines the results reported in 13 qualitative original research reports, published in peer-reviewed nursing journals between April 1998 and June 2006. We used thematic analysis. Three themes were formulated: “running into an unpredictable enemy”, “enduring a fading body” and “entering social silence”. Patients and family members gave voice to a suffering that involved the whole person. Our findings show that the whole person must be given care, and this care must include the whole family.

Key words: Meta-analysis, illness experiences, upper gastrointestinal cancer, head and neck cancer, thematic analysis, patient and family perspective

Introduction
Illness can be described as human experiences of symptoms and suffering, a definition that refers to how a disease is perceived and lived with by individuals and their family members (Kleinman, 1988). Cassel (1982, p. 640) defines suffering as a “state of severe distress associated with events that threaten the intactness of the person”, and points out that traditional medicine and nursing have mainly concentrated on the body and the disease. The focus of medicine and nursing has gradually shifted from this “outsider perspective” to an ‘insider perspective’ with focus on the sick person’s own experiences of illness (Thorne & Paterson, 1998). Still, traditional professional health-care expertise cannot sufficiently cope with the claims of this insider perspective (Thorne, Ternulf Nyhlin, & Paterson, 2000). In Sweden, the Health and Medical Services Act (SFS 1982:763) stipulates that the patient has the right to be involved in his or her care and treatment of the disease. A disease refers to problems related to the biological dimensions such as alternations in structure and function. Illness, however, is the human experience of symptoms and suffering referring to how the disease is lived with and responded to by the patients and their families (Kleinman, 1988). Thus, health-care professionals need to understand the concept of illness and how illnesses are experienced by patients and family members in their everyday life.

Research reports about oesophageal cancer, upper gastrointestinal cancer, and head and neck cancer describe aspects such as bodily changes in patients (De Boer, McCormick, Pruyn, Ryckman, & van den...
Borne, 1999; Verschuur et al., 2006); emotional distress (De Boer et al., 1999; Winterling, Wasteson, Glimelius, Sjöden, & Nordin, 2004), and existential concerns experienced by patients and family members (Abma, 2005; Gamble, 1998). Studies have shown that patients with these diseases and other types of incurable cancer experience loneliness and social isolation (De Boer et al., 1999; Kuuppelomaki & Lauri, 1998; Rydahl-Hansen, 2005; Winterling et al., 2004), leading to severe suffering for both patients and family members (Kahn & Steeves, 1995; Kuuppelomaki & Lauri, 1998). Cassel (1982) describes how suffering often parallels bodily symptoms, and points out that suffering extends beyond the physical manifestations, involving the complete person. In every day work, nurses and other health-care professionals encounter patients and family members who are suffering. Alleviation of suffering is one of the main aims of caring (Eriksson, 1992), and nursing care requires empathic understanding and sensitivity for patients’ and family members’ experiences and needs. Nursing (as well as professional health care in general) needs to develop a discourse of care based on knowledge derived from patients’ and families’ insider perspective of illness.

This study is part of a research program the aim of which is to generate knowledge about patients’ and family members’ experiences of living with oesophageal cancer. The aim of this study was to extend this knowledge. As there are few studies dealing with only oesophageal cancer, this study has included studies of other upper gastrointestinal cancers (mainly head and neck cancer) where similar research aspects were included. The reason for this is that questions of survival and patients’ experiences, mainly concerning food intake, are similar between the cancers (Homs, Kuipers, & Siersema, 2005; List & Bilir, 2004a,b).

Method

A meta-analysis of qualitative studies

The meta-analysis approach was chosen since it allows interpretation of findings deriving from a group of qualitative research into one explanatory interpretative end product (Paterson, Thorne, Canam, & Jillings, 2001; Stern & Harris, 1985). Meta-analysis differs from traditional or critical literature review in that it not only aggregates the findings but also interprets them (Paterson et al., 2001) for the purpose of a fuller understanding of the phenomenon (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). Terms used to describe the synthesis of qualitative research findings include “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) make a distinction between the processes of analysis and synthesis. According to them, a meta-synthesis involves synthesising not only the findings, but also the methodological and theoretical perspectives of the primary research, and the historical and sociocultural context in which they occur. Our intention was to analyse solely the findings of the original reports, which is why we have chosen to use the term “meta-analysis” throughout the present study.

The research team

Paterson et al. (2001) make it clear that meta-analysis is a team effort, and the team must be able to apply multiple perspectives and reflect about these perspectives. The research team that conducted the present study consisted of four investigators. The first author (SA) is a registered nurse with clinical experience of surgical and oncological nursing, primarily within the upper gastrointestinal tract. Her pre-understanding comes from her work as a nurse where she met patients with oesophageal cancer and their family members. These encounters made her reflect upon patients’ and family members’ situation and she became interested in how they experience living with oesophageal cancer. The other three team members are senior lecturers in nursing and researchers, skilled and experienced in the use of qualitative methods.

We compiled written guidelines that described the role and duties of each team member. These guidelines stated that all members contributed as equal partners, that all team members were involved in all aspects of the research process, and that the first author for practical and educational reasons had the main responsibility for planning and completing the project. Working in a team, we communicated and discussed differences in opinion arising in the course of the analysis.

Locating research reports

We used a combination of strategies to locate original research reports. First, we carried out searches in several databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), MedLine (accessed via PubMed), PsycInfo, and SweMed. Before performing the main searches, several test searches were performed. Since 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 of the present study. For that reason, the searches were limited to nursing journals, resulting in a manageable amount of reports. 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. Second, we searched textbooks in oncology for appropriate chapters, and examined the reference lists of these chapters. Third, we examined reviews and their reference lists. The final strategies for locating reports were to check all reference lists in reports that were already included in the meta-analysis, and those of reports that had been excluded through the appraisal procedure; and to check all “related articles” that Medline gave in for those reports had been included in the study. No additional reports were found at the second and third stages. The searches were performed during November and December 2005.

Inclusion and exclusion criteria

Inclusion criteria for this study were that a report must be a qualitative original report written in English or any of the Scandinavian languages, describing patients’ and/or family members’ experiences of living with oesophageal cancer, different upper gastrointestinal cancer, or head and neck cancer. We used the definition of ‘qualitative study’ proposed by Sandelowski and Barroso (2003): empirical research with human participants, conducted in any research paradigm that used qualitative research methods.

We excluded reports that fulfilled one or more of the following conditions: (a) the use of mixed methods, where qualitative findings could not be separated from quantitative findings; (b) the use of mixed samples in which findings for upper gastrointestinal cancer and head and neck cancer could not be separated from other cancers; (c) editorials or other reports that lacked original research results; and (d) reports in which the author(s) said it was qualitative but in fact it was a survey or the data was presented as numbers or lists without narrative or textual quality. No reports were found in any of the Scandinavian languages.

The electronic searches revealed more than 150 reports. The first author reviewed these reports first by title, then by abstract and finally by full text. Reports that did not meet the inclusion criteria were excluded at each stage. This left 23 reports, which were discussed in the team. This allowed us to exclude ten further reports. Authors were contacted by e-mail in two cases in order to determine which cancer forms were included. These contacts resulted in exclusion of the reports concerned. After further discussions, we excluded another eight reports, because we found that these reports did not have the illness experiences clearly expressed in their findings or lacked original research results.

Thus, 13 reports, comprising studies from eleven projects, matched the inclusion criteria and were included in this study (Table I). Eight original reports focused on patients’ experiences, one report focused on family members’ experiences, and four reports on both patients’ and family members’ experiences.

Data analysis

There is no single data analysis technique and procedure applicable to analysis of data in a meta-analysis: Paterson et al. (2001) state that any interpretive method can be applied the choice depending on the purpose of the meta-analysis. We have performed a qualitative content analysis, in this case a thematic analysis as described by Patton (2002), since our aim was not only to describe elements that were physically present in the text but also to interpret the core meaning of the data, i.e. to search for prominent themes. According to Patton (2002), the mechanical work of thematic analysis involves two phases, a descriptive phase as well as an interpretative phase. The analysis was performed as follows:

In phase one, the team members read each report independently in order to make sense of the complexity of the reports. Key phrases (i.e. a string of words, a sentence, or several sentences bound together by their content) that answered the aim of the present study were thereafter defined to break up the reports into distinguishable parts. We then identified the characteristics of each key phrase and gave it a code. We had to read each paper several times in order to encode completely the key phrases. The coding process allowed us to identify recurring regularities in the data. The codes were sorted into preliminary categories using coloured highlighting pens. We verified the accuracy of these preliminary categories by working back and forth between the data and the classification system. More than one person analysed the reports, but each member developed a coding scheme independently, i.e. each of us identified key phrases, coded them and classified them independently, as Patton (2002) recommends.
| Author/s  |
|----------|
| Year of publication |
| Country where the study took place |
| Study characteristics | Participant characteristics |
| Objective | Method | Main findings | Participants |
| Data Collection | Data Analysis | Site of cancer |
| | | | (W = women, M = men) |
| *Andreassen et al. 2005 Sweden | To describe family members’ experiences, information needs and information seeking in relation to living with a patient suffering from oesophageal cancer. | Semi structured interviews | Content analysis, induction and deduction | Family members unprepared and unaware of the diagnosis. The illness caused uncertainty and intrusions on the family. | 9 (W = 6, M = 3) | Oesophageal cancer |
| *Andreassen et al. 2006 Sweden | To describe patients’ experiences of living with oesophageal cancer and how they seek information. | Qualitative, semi-structured interviews | Qualitative content analysis, induction. | Patients were unprepared for receiving the diagnosis. Symptoms and uncertainty influenced their every day life. Sought information to handle the illness. | 13 (W = 6, M = 7) | Oesophageal cancer |
| Edwards 1998 UK | To find out what patients, their families and professionals thought of head and neck cancer services. | Focus groups | The content of the data were analysed for themes and key issues. | Both patients and family members experienced difficulties in contact with care services. | 22 | 11 | Head and neck cancer |
| Fritz 2001 USA | To describe the phenomena of surviving head and neck cancer in patients with a history of cigarette use for a minimum of three years or who are currently smoking. | Qualitative interviews | Phenomenology | Patients experienced feelings of guilt, anxiety, helplessness, self-image disturbances and depression. | 3 (W = 1, M = 2) | 2 tongue cancer 1 unknown primary cancer of head and neck |
| Jones 2001 UK | The study explores psychoanalytic ideas of containment as described by Wilfred Bion and applies them understanding the concerns of a woman with serious illness and her husband. | Psychoanalytically informed conversation | A psychoanalytic interpretation | The patient felt she had to fight to receive attention from health-care providers. | 1 (W = 1) | 1 (M = 1) | Head and neck cancer |
| Author/s | Year of publication | Country were the study took place | Study characteristics | Participant characteristics |
|----------|---------------------|----------------------------------|-----------------------|-----------------------------|
| Larsson et al. | 2003 | Sweden | To acquire a deeper understanding of head and neck cancer patients' lived experiences of eating problems, the consequences of them in daily life and the strategies for coping related to these problems during radiotherapy. | Interviews in form of an open dialogue | Interpretive phenomenology | Eating problems is a complex phenomenon. Eating problems caused severe consequences in daily life. | 
| Moore et al. | 2004 | USA | To gain a deeper understanding as to why patients with SCCHN primary stage disease underreport their experiences of suffering to their clinicians. | In-depth, semi-structured interviews | Thematic analysis | Patients were self-diminished by the cancer. They experienced fear of addiction to medications, hopelessness and loss of meaning in life. They under-report their experience of suffering because of fear. | 
| Olsson et al. | 2002a | Sweden | To record and describe patients' experiences of their intake of food and fluid, appetite, hunger, and changes in weight during the three months following GI surgery. | Qualitative interviews | Qualitative content analysis | Patients struggle to eat and drink. They experience bodily estrangement. Their eating difficulties caused feelings of isolations and limited their social life. | 
| Olsson et al. | 2002b | Sweden | To describe patients experiences of the convalescent or recovery period 3 months after GI surgery. | Interviews in form of conversation | Hermeneutic | Patients felt lonely, abandoned and disappointed during the recovery period. Their suffering was seen as a fight between lack of freedom and freedom, including feelings of hope and doubts. | 

| Participants (W = women, M = men) | 
|-----------------------------|
| Patients | Family Members | Site of cancer |
| 8 (W = 2, M = 6) | 6 larynx cancer | 6 larynx cancer |
| 18 (F = 5, M = 13) | 4 oral pharyngeal cancer 3 oral cavity cancer | 4 oral pharyngeal cancer |
| 15 (W = 6, M = 9) | 2 larynx cancer 2 oesophageal cancer | 2 larynx cancer 2 oesophageal cancer |
| 10 (W = 4, M = 6) | 1 hypopharynx cancer 1 Gi cardiac cancer | 1 hypopharynx cancer |
| | 6 gastric cancer 4 oesophageal cancer | 6 gastric cancer 4 oesophageal cancer |
| | 2 pancreatic cancer 2 Gi cardiac cancer | 2 pancreatic cancer 2 Gi cardiac cancer |
| | 1 gastric lymphoma 5 gastric cancer | 1 gastric lymphoma 5 gastric cancer |
| | 2 oesophageal cancer 1 pancreatic cancer | 2 oesophageal cancer 1 pancreatic cancer |
| | 1 cardiac cancer 1 gastric lymphoma | 1 cardiac cancer 1 gastric lymphoma |
| Author/s          | Year of publication | Country where the study took place | Study characteristics                                                                                      | Participant characteristics |
|------------------|---------------------|-----------------------------------|------------------------------------------------------------------------------------------------------------|-----------------------------|
| Richardson et al. 2002 UK | To learn the views of patients and their carers on a set of regional standards, developed by clinicians. | Focus groups | Patients felt profoundly changed as a result of their experiences living with cancer. They felt awkward appearing in public because of eating difficulties or altered appearance. | 39 Patients, 18 Family Members, Head and neck cancer |
| Watt & Whyte 2003 UK | To explore the experiences of dysphagia in oesophageal cancer and how this affects quality of life. The aim of this study was to add knowledge and comprehension of this poorly understood symptom. | Semi-structured interviews, Phenomenology | Patients experienced dysphagia as a troublesome symptom that affected all aspects of quality of life. | 6 (W = 5, M = 1) Oesophageal cancer |
| Wells 1998 UK | To examine what really happens to patients with head and neck lesions during the period in which we expect them to be “recovering” from radiotherapy. | Diary-interview method, symptoms card, Qualitative content analysis | The impact of radiotherapy and the disruption to daily life is shown by the uncertainty and unpredictability of symptoms, the waiting, the ambiguity and loss of self integrity that occurred throughout the radiotherapy treatment. | 12 Patients, Head and neck cancer |
| Yi & Kahn 2004 Korea | To explore the experiences of gastric cancer couples. The specific aims of this study were to explore major problems that the gastric cancer couples faced and how they resolved these problems. Ultimately, it was to generate a substantive theory integrating the experiences of gastric survivors and their spouses as a whole. | In-depth interviews, Constant comparative analysis | Patients and their spouses experienced critical problems that occurred in their everyday life. Emotional conflicts occurred between the couples because they had difficulties handling their emotional distress. | 11 (W = 2, M = 9), 11 (W = 9, M = 2) Gastric cancer |

*These two studies are from the same project. **These two studies are from the same project.
Increased understanding emerged from the different ways in which we classified the data.

The team met on a regular basis to compare and discuss similarities and differences in our coding. The first author collected all members’ key phrases, codes, and categories, compared them, and created a tentative joint classification system. We then met several times and discussed this classification system. Based on these discussions, the codes were classified into descriptive categories engaging existential/psychological/physical/social experiences.

In phase two, the descriptive categories built a foundation for the interpretation where we compared and interpreted the data within these categories, and we determined the significance of the categories and extracted the underlying meaning (cf. Patton, 2002). As a result of this analysis in phase two, three themes emerged “Running into an unpredictable enemy”, “Enduring a fading body” and “Entering social silence”.

**Ethical considerations**

We have striven to ensure and to verify that our interpretation of the findings is based on data reported in the original studies. All original studies have been published in peer-reviewed journals, 11 out of 13 stating that they have ethical approval from a committee of research ethics.

**Findings**

We introduce below the themes that our analysis revealed, and present our findings in an interpretative manner. We then present each theme in a descriptive way. Table II shows the core of each theme, and its categories and properties. These will be integrated in the following text. Each theme will be illustrated by direct quotations from the original reports.

**Running into an unpredictable enemy**

The diagnosis precipitates a crisis, as patients and family members are confronted with a fatal illness and aggressive treatment. They experience cancer as a death threat, which evokes strong emotions. Patients and family members lose certainty about health and life, and the resulting uncertainty is profoundly stressful. The stress leaves them physically and mentally exhausted. Uncertainty about the future makes them feel out of control. Having cancer is like fighting a battle against an unpredictable enemy.

*The descriptive presentation.* The cancer diagnosis evokes shock, stress, disbelief, and feelings of being on “a knife edge” (Wells, 1998, p. 845) in patients and family members. A woman in the study by Watt and Whyte (2003, p. 187) who received the diagnosis of cancer expressed: “I was absolutely stunned, I remember lying in my bed, turning my face to the wall after [consultant] told me and I just cried”. Family members generally indicated they had not anticipated that the patients’ physical problems could mean anything as sinister as cancer. A spouse in the study by Andreassen, Randers, Näslund, Stockeld and Mattiasson (2005, p. 429) stated that it was a shock that such a life-threatening illness was concealed. Patients in several of the studies included in this meta-analysis described how being given the cancer diagnosis was like being given a death sentence: “Oh my God! I’m going to die!” (Yi & Kahn, 2004, p. 629). Both patients and their family members expressed metaphors of being “struck down” by the impact of the diagnosis. A patient in the study by Olsson, Bergbom and Borseus (2002a, p. 54) stated, “When I was told that I had cancer in my stomach I became scared. I must say that I was just like being felled like a tree”. A spouse in the study by Andreassen et al. (2005, p. 429) expressed that she had no idea about this diagnosis, and that was tremendously bewildering for her.

Spouses feared for their partners’ death and a subsequent life without him or her. Children were aware of the seriousness of their parent’s illness and they became anxious and distressed, which in turn caused an imbalance in their own lives. A father in the study by Andreassen et al. (2005, p. 430) described: “Our son had his 18th birthday this year. Although he himself says that his mother’s illness doesn’t affect him at all, we have noted that his grades dropped disastrously during his first term”.

Patients became anxious when told about the harrowing and extensive treatment. One woman in the study by Edwards (1998, p. 101) described her feelings after being informed about the surgical procedures: “When I was told what they were going to do with me I was shell-shocked. I really thought it sounded like a horror film”.

Patients experienced a continuous worry about the effect that the treatment would have. They considered waiting and not knowing what would happen to be the worst part of the illness. A patient in the study by Wells (1998, p. 845) stated: “The waiting is the worst bit of this whole business — what is going to happen to me?”

Family members lived in apprehension, waiting for the inevitable: relapse of the cancer or death of their partners. Uncertainty about the future raised many questions expressed in the study by Andreassen et al. (2005, p. 430): “Shall we sell the houses or shall we not? Shall we renovate our house or shall we not?
Shall I work full time or shall I not? Will my husband die tomorrow or not?". Patients and family members lived with daily fear and anxiety of deterioration or a recurrence of cancer. A spouse in the study by Yi and Kahn (2004, p. 629) expressed: “The thought of recurrence of cancer always hovers in the back of my mind. If he says that he feels something in his belly, all of a sudden my heart stops”.

### Enduring a fading body

Patients suffer from physical discomfort, arising from sinister, complex and serious symptoms and side effects of treatment. They lose their ordinary daily life and they must adapt to physical restrictions that make them feel overwhelmed and captured by the disease. There is a continuous struggle to survive. Alterations in physical functions and appearances affect patients’ body image and self-confidence. These changes confront both patients and family members with the seriousness of the disease. Family members are eyewitnesses to how the patients’ bodies fade, and they suffer from patients’ distress.

**The descriptive presentation.** “The throat is like a big burn. The palate likewise and the tongue… the tiniest little thing that gets into the mouth creates...”

| Themes | Categories | Properties |
| --- | --- | --- |
| Running into an unpredictable enemy | Life changes suddenly and unanticipated for patients and family members. | Shock, Stress, Disbelief, Receiving a death sentence, Being on a knife edge |
| | Uncertainty, fear and anxiety of the progress of the disease is present persistently in patients and family members. | Anxiety, Fear, Distress, Waiting, Uncertainty, Fighting an unending battle |
| Enduring a fading body | Patients experiences of manifest physical symptoms and side effects of various treatments. | Common physical side effects, Painful, Difficult, Suffering, Feelings of shock, All-encompassing fatigue, Severe restrictions in diet, Takes longer time than normal to eat, Depressed and unhappy, Reluctance to eat, Eating a chore, not pleasure, Alienation with their bodies, Loss of self-confidence, Changes in body image |
| | Meals become time consuming because of patients’ difficulties in eating and drinking and their experiences of eating change from pleasure to discomfort. | |
| | The physical alterations of the disease lead to loss of self-confidence and changes in patients’ body image. | |
| Entering social silence | Patients’ and family members’ daily life become restricted and bound to their homes. Discomfort and embarrassments affect relationships with friends and family and thereby social life. | Daily life restricted, Bound to their home, Embarrassment, Disgust, Shame, Awkwardness, Reluctant to socialise, Withdrawal from society, Dependence of their spouses, Conflict of interests between family members, Relationship unstable and frail, Need to talk to professionals, Powerlessness, Loneliness, Abandonment, Family members feel invisible |
| | Relationships between spouses affected. | |
| | Patients and family members have many questions, but they feel isolated and abandoned not knowing with whom, within the health care system, to talk. | |
Dante’s inferno—hell” (Larsson, Hedelin, & Athlin, 2003, p. 566). This quote is an example from the study by Larsson et al. (2003) of how the side effects of radiotherapy may be felt. Side effects, such as sore or dry mouth and throat, made it painful to eat and swallow, and sometimes also difficult to breathe. A woman in the study by Fritz (2001, p. 11) described:

I sometimes swallow a pill—think I swallow it, but my mouth is so dry it might be stuck somewhere. It doesn’t go down. And when I talk about dry mouth the radiation doctor said, ‘Oh, you’ll get used to that.’ He has no idea what this dry mouth is. None of them do. This is so dry, like I say, if I put a pill in my mouth it sticks right where it lands and I can hardly swallow because the dryness goes into the throat.

Diarrhoea, nausea, vomiting, and dumping syndrome were common gastrointestinal problems after surgical and oncological treatment. A patient in the study by Olsson et al. (2002a, p. 55) expressed this strongly: “I just had to go to the toilet and just hoped nobody got in my way”.

Patients’ hearing was affected by chemotherapy, which made them feel like “living in a vacuum” (Andreassen, Randers, Näslund, Stockeld, & Mattiasson, 2006, p. 690). The impairment in hearing was especially hard for one patient in the study by Fritz (2001, p. 11):

I can’t hear out of one ear and I sound like Daffy Duck. What I hear coming out of my mouth in hospital sounded like Daffy Duck. In fact, I can do a hell of an impersonation of Daffy Duck when I want to, but that bothered me. After discharge that still bothered me because I think how I am going back to work as a nurse when 70% of what I do is communication and it’s quick communication.

Fatigue was experienced by patients as an everyday symptom of general tiredness or lack of energy and strength. This fatigue overshadowed everything. It dominated the patient completely, and it could be triggered by the disease itself, weight loss, investigations, harrowing and extensive treatment, or information about treatment. The paralysing tiredness was described by a patient in the study by Larsson et al. (2003, p. 567): “You can’t imagine this tiredness. You are so incredibly tired … it’s paralysing. You can’t stay awake”. Fatigue decreased patients’ ability to move without restriction or assistance. Their emotional equilibrium was disturbed and their power of initiative was reduced. Physical discomfort and anxiety caused disturbances in their sleeping patterns, and this increased tiredness. Spouses were physically drained after treatment, as they had devoted their entire energy to taking care of everyday routines such as food preparation. A patient may require the spouse to prepare all meals, leading to this statement from a spouse in the study by Yi and Kahn (2004, p. 629): “I am living in the kitchen 24 hours a day … Even now [eight months after surgery] he doesn’t eat for lunch what was prepared for breakfast. . . He seems to think I am made of steel!”

Eating problems and the side effects of treatment caused patients to modify the type of food they ate, and severely restrict the diet. Patients were forced to eat mashed or liquid food, or to take small bites. Disfigurement and dysfunction made it strenuous to chew and swallow, and it took longer than normal to eat. It was hard to overcome the physical difficulty in chewing and swallowing.

Patients experienced changes in taste and appetite, yet they sometimes longed for food. Lack of appetite or the inability to eat normally caused them to feel depressed and unhappy. Alterations in saliva production or the smell and sight of food precipitated nausea and made some of them reluctant to face food. A woman in the study by Andreassen et al. (2006, p. 690) said that she could not eat the same food as she used to eat and that she had no appetite right now. She further said that cooking was no fun, and that nothing tasted good any more. She tried to eat sour milk, but she kept vomiting. She had an enormous amount of phlegm and it really bothers her.

Patients forced themselves to eat because they knew that they would die of malnourishment if they did not eat. The pleasure of eating and drinking changed from joy to discomfort. A patient in the study by Olsson, Bergbom and Bosaesu (2002b, p. 149) said: “You know you have to eat. But it is not much fun to have to force yourself”. Eating habits, mealtimes, and diet were altered for the family because of patients’ difficulties in nutritional intake. Preparing food was not always an easy task for spouses.

Weight loss affected patients before diagnosis, and subsequently as a side effect of surgical and oncological treatment. Losing weight caused not only physical discomfort; it caused also a feeling of shock when they saw their bodies. Many patients hated their bodies after considerable weight loss, and perceived it as a skeleton. Gaining weight was always on their mind, so that they could regain their previous appearance. A woman in the study by Watt and Whyte (2003, p. 189) said:
Well to be honest it just makes me not want to look at my own body. I hate it... ‘That’s me a blooming skeleton’ but no it definitely takes your life away there is no getting away from it. I just feel as though I am standing at a bus stop waiting for a funeral procession to come up and that’s it.

Facial dissection, side effects of radiotherapy, and surgery caused facial disfigurements, which were experienced as traumatic. These visible bodily alterations caused the patients to feel alienated from their own bodies. Patients felt that they were not the person they used to be. A patient in the study by Richardson, Lee and Birchall (2002, p. 1033) reminisced:

Cancer is with us forever either in its after-effects or in its recurring stages.... You’re no longer the person that you used to be, an air traffic controller and a singer in the local choral society. You are a person who’s got that funny thing in his throat and that we all feel sorry for.... It changes your life.

**Entering social silence**

Patients and family members feel abandoned and lonely, and enter a social silence. The illness intrudes into family life and family routines and restricts their range of activities. Patients experience social awkwardness and a self-induced withdrawal from social interactions, a process that is triggered by symptoms and side effects. Both intimate relationships and social contacts within and outside the family are broken. Patients and family members feel abandoned not knowing with whom within the healthcare system to discuss their feelings and concerns. This increases their feelings of loneliness. The lack of a supporting person causes suffering. The illness affects the relationship between spouses: they are inclined to become irritated and easily annoyed at each other, and conflicts occur. Family members feel diminished in their contacts with health care services.

The descriptive presentation. The daily lives of patients and family members became restricted. They were more bound to their homes since they could not travel or live the life they considered normal. Ordinary everyday activities such as going for a walk or catching the bus were difficult. A woman in the study by Andreassen et al. (2006, p. 690) described how she lived: “I am terribly, terribly tired. Certainly, I am out walking every day, but not very long stretches. I must stop quite often to breathe and to rest”.

Patients experienced ever-present feelings of embarrassment, disgust, and shame because of difficulties in eating, difficulties in talking, bad breath, increased amount of saliva, and facial disfigurement. This made patients reluctant to socialize. They felt awkward in public and withdrew from society, expressed in the following quotes from the original articles: “Didn’t go to church because I didn’t want people looking surreptitiously at my burns” (Wells, 1998, p. 845). “It is this sticky saliva in my mouth and the metallic taste that makes me believe that I smell bad to everyone.... I don’t want to be with anyone” (Larsson et al., 2003, p. 567). “I don’t want to be embarrassed trying to eat.... I do miss the company” (Watt & Whyte, 2003, p. 191). The thought of visiting a restaurant was described by a patient in the study by Watt and Whyte (2003, p. 190) like putting her head in the lion’s den. Eating at home as a family could also be disturbed, which led to a loss of togetherness and to social isolation for patients and family members. A spouse in the study by Andreassen et al. (2005, p. 429) expressed it this way:

Usually we sit together at supper and talk about the day. Then we share our lives with the entire family. It’s very much a sharing opportunity. However, eating together is no longer associated with pleasure because my husband is not able to eat due to his dysphagia.

Living with enteral tube feeding was demanding and strenuous, and it restricted the patients’ range of daily life activities and time for social contacts. This in turn led to withdrawal from public places. A man in the study by Andreassen et al. (2006) said that the peg was an obstacle when he showers and when he travels. He further said that he could not go to a public sauna and places like that.

Patients experienced feelings of worthlessness, since they were not able to carry on with meaningful professional work. The loss of social contact with colleagues contributed to social isolation and feelings of worthlessness. A woman in the study by Fritz (2001, p. 11) recalled: “I did a lot of volunteer work and now it is difficult for me to do anything and I just feel worthless now. I don’t feel I’m contributing in any way”.

Patients with head and neck cancer often had difficulties talking in an articulate way and people did not understand them. The patients became embarrassed and they did not willingly talk to other people.

The omnipresent and overwhelming fatigue promoted a dependence on the partner concerning care and various chores. The relationships between
patients and their spouses became unstable and frail. Unemployment, emotional distress, and overreaction sometimes made it difficult to tolerate each other and induced disputes. A spouse in the study by Yi and Kahn (2004, p. 631) said:

Accepting his frustration and anger was so hard. For everything I said, he got irritated and emotional for no reason… So it got me to the point were I said things I didn’t really mean. Though I try to understand him, I am a human being too, you know.

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. They felt that professionals failed to meet their unique needs. Patients and family members were offered little psychological support after discharge from hospital. Patients felt a need to discuss feelings of guilt that arose from the idea that they themselves had promoted tumour growth by their way of living. A woman in the study by Moore, Chamberlain and Khuri (2004, p. 58) reflected:

I am a recovering alcoholic. Yes, I smoked for 30 years but I quit 8 years ago in 1992. I stopped drinking 11 years ago. // I felt this [the cancer] was my entire fault. I brought it on myself because of my inability to deal with life.

Patients and family members felt they had to fight to attract the attention of health-care professionals when visiting hospital. They were afraid of being regarded as time-wasters, or appearing to be a nuisance or silly. One woman, in the study by Jones (2001, p. 462), who had her vocal cords removed expressed this in writing: “They say they are too busy or they have treatments and dressings to do, which are important, but I haven’t got a voice and I feel degraded. I am no-one” A man in the study by Wells (1998, p. 844) recalled:

I didn’t want to delay them because of the next person hanging on… I’m quite certain they probably felt as far as I was concerned oh, he’s all right, he doesn’t need any help, because, I wasn’t moping or streaming with tears.

Feelings of loneliness were induced when patients did not have the opportunity to share thoughts, feelings and experiences with fellow patients who had been through the experience of cancer and who could provide information and hope for patients’ own prognosis. A patient in the study by Richardson et al. (2002, p. 1033) said that it was easier to ask someone who had gone through the same illness: “Little problems that you can’t ask a doctor—a doctor doesn’t know—you can ask someone else and they say ‘oh, yes, I had that’ ”. A woman in the study by Moore et al. (2004, p. 58) reminisced that there were no women with this disease that she knew of at that time. She was the only one. She guessed that was why she was feeling lonely.

Family members were more distressed by the illness than patients were, and this was expressed by both family members and patients. Family members felt invisible and ignored in their contacts with the health-care system. Their informational and emotional needs were neglected, and they did not receive the support they needed. A spouse in the study by Andreassen et al. (2005, p. 429) expressed: “We [family members] are probably only an appendage”.

**Comprehensive understanding of findings**

Living with oesophageal cancer and clinically similar forms of cancer implies both for patients and their family members, uncertainty, alienation against the patient’s body, feelings of embarrassment, reluctance to socialise outside their home leading to loneliness and isolation. Both patients and family members feel abandoned as they experience that their unique needs are not met by health-care professionals.

**Discussion**

This meta-analysis is based upon thirteen original reports. It is not possible to specify the number of reports that should be included in a meta-analysis. The number is depending on both the breadth of the topic, the state of the art of the topic, and the amount of data available in each report included in the meta-analysis (Finfgeld, 2003; Paterson et al., 2001). Paterson et al. (2001) give an arbitrary number of twelve reports, which harmonise with the amount of the present meta-analysis.

Most of the work described in these reports was conducted in Sweden and the United Kingdom (see Table I), and only one report described work carried out in Asia. One original report focused on family members (Andreassen et al., 2005) and four reports (Edwards, 1998; Jones, 2001; Richardson et al., 2002; Yi & Kahn, 2004) on both patients and family members. 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 focuses on the palliative phase of cancer, or discussed issues regarding the dying process, even though the reports
described patients’ and family members’ experiences of cancer as a mortal threat and their uncertainty about survival.

It was difficult to find qualitative research, as the thesaurus terms used in reference databases’ indexing system are not designed specially to identify qualitative research (Shaw et al., 2004). We tested many different search terms, and we believe that we discovered the most productive set—the set that enabled us to find most of the eligible reports.

The reports in this meta-analysis describe a range of theoretical and methodological approaches. Some researchers believe that studies included in a meta-analysis must have used the same methodological approach (Estabrooks, Field, & Morse, 1994). Others disagree. Jensen and Allen (1996), for example, argue that it is not the studies in themselves that are of interest, it is the experiences that are reported in the studies that are of interest. We have included reports that use different methods, where the experiences of the illness were clearly expressed in form of quotations and narratives. This has given a richer and more multifaceted understanding of the experiences in which we were interested (cf. Paterson et al., 2001).

Paterson et al. (2001) show that a qualitative meta-analysis is a demanding team effort. Three of the present authors (SA, IR, ACM) have previously worked together. We invited a fourth researcher (KTN) onto the team, because we recognized how important it is to see things with fresh eyes, and how this would enhance creativity. Our different pre-understandings and research experiences ensured a reflective, vivid, and fruitful dialogue. It has been a challenging task to interpret the data, but the dialogue established within the team allowed us to seek explanations other than our original ideas and thoughts, and we were able to agree upon a mutual analysis.

In this study, we have described patients’ and family members’ experiences of living with oesophageal cancer, other upper gastrointestinal cancer, and head and neck cancer in three themes: running into an unpredictable enemy; enduring a fading body; and entering social silence. For a better understanding of their experiences and difficulties we have found it useful to reflect upon our findings in light of the concept of suffering by Cassel (1982, p. 640), who states that suffering is “the state of severe distress associated with events that threaten the intactness of the person” and Eriksson (1992, p. 123), who describes suffering as “the experiences of something that hurts”.

The overall findings expressed in the three themes in this meta-analysis are that patients and the whole family experienced a crisis as they were confronted with the lethal cancer illness and the aggressive treatment. The uncertainty from loss of health and life was overwhelmingly stressful. The illness intruded into the family and restricted their routines, range of activities, and life plans.

The suffering experienced by patients and family members had a clear physical foundation: the symptoms of cancer and the side effects of treatment. However, suffering extended beyond these physical manifestations, and we show in this meta-analysis that patients’ and family members’ suffering expressed in the three themes is an entity. This is consistent with Cassel (1982) who states that it is neither possible nor feasible to divide individuals’ experiences of suffering into separate physical, psychological, and social aspects since it is experienced by the person, and not by his or her body or mind. This meta-analysis shows that the restrictions in physical functions and altered physical appearance changed the image that patients had of their own body, which resulted in many cases in an aversion to it.

These findings are consistent with Cassel (1982), who describes that a disease can turn a person’s body into an enemy. The transformation from friend to enemy may be experienced more intensely if the disease comes without warning, as is often the case with oesophageal cancer, upper gastrointestinal cancer, and head and neck cancer. Our findings show that patients experienced that they were no longer the same person as before their body faded.

Further, patients and family members gave words to a suffering arising from the disruption of their social world and relationships, as has been found also by Kuuppelomaki and Lauri (1998) and by Rydahl-Hansen (2005). Cassel (1982) states that persons suffer from the absence of routines when illness restricts their range of activity. This meta-analysis shows that patients’ physical discomforts caused feelings of social awkwardness and a self-induced withdrawal from social interaction. This, and the failure of health-care professionals to address patients’ and family members’ unique needs, caused feelings of abandonment and lonelines. In addition, family members are frustrated that they cannot be more helpful when patients are suffering.

We found that not only patients, but also family members, gave words to a suffering caused by the illness, as has been described by Abma (2005) and by Cassel (1982). Health-care professionals paid limited attention to family members which caused suffering, earlier described by Abma (2005) and by Cassel (1982). This could be because family members do not often articulate their own needs in contact with health-care. Persons do not often talk spontaneously about the source of their suffering,
Cassel (1982) points out. One way to know if and when a person is suffering is to ask the person directly. Hence, health-care professionals must invite both patients and family members to express their feelings and needs. Tailored assistance and attentive listening by health-care professionals, and the expression of authentic empathic understanding, will help patients and family members to put their experiences of suffering into words.

Patients and family members felt that health-care professionals focused on treatment and symptoms, but failed to recognise emotional and existential concerns. This has been described also by Abma (2005) and by Cassel (1982). Eriksson (1992) emphasizes that the alleviation of suffering is the primary goal of caring, as it helps a person to endure his or her situation. When health-care professionals fail to satisfy the needs of patients and family members for support, this failure becomes a source of suffering (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Cassel, 1982; Eriksson, 1992).

This meta-analysis describes patients and family members who experienced suffering that involved the whole person. Further, it shows glaring weaknesses in knowledge regarding medical and nursing care providers. Consequently, patients and family members feel neglected and abandoned by the health-care system.

In this meta-analysis based on qualitative research reports, we have tried to obtain knowledge from an insider perspective about living with oesophageal cancer and similar cancer forms. Indeed, we have increased our own knowledge by reading and analysing these reports. A concluding significant question is whether we have fulfilled the purpose of the study—to provide extended knowledge, for the benefit of patients and family members concerning their care. Indeed, what could be learned from our meta-analysis is that the situation for these patients and their family members is just as difficult and that there is as much suffering as we describe.

Knowledge derived from a meta-analysis should be more substantial than what already could be learned from the individual original reports (Finfgeld, 2003; Paterson et al., 2001; Thorne et al., 2004). We hope that is the case in this meta-analysis. We believe after analysing these reports that there is a tendency that health-care professionals have not developed knowledge enough to be able to give patients and family members appropriate tools to handle their practical situations. According to the stipulation in the Swedish legislations and the discussions that have been held, this must be taken into consideration.

More research from an insider perspective needs to be initiated and carried out to more fully understand patients’ and family members’ practical and existential concerns. Our suggestion for future research is to focus on how to cope with the illness experiences and the suffering following the illness as care must be provided for the whole person, and it must include the whole family.

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References
Abma, T. A. (2005). Struggling with the fragility of life: a relational-narrative approach to ethics in palliative nursing. Nursing Ethics, 12(4), 337–348.
Andreassen, S., Randers, I., Näslund, E., Stockeld, D., & Mattiasson, A. C. (2005). Family members’ experiences, information needs and information seeking in relation to living with a patient with oesophageal cancer. European Journal of Cancer Care, 14(5), 426–434.
Andreassen, S., Randers, I., Näslund, E., Stockeld, D., & Mattiasson, A. C. (2006). Patients’ experiences of living with oesophageal cancer. Journal of Clinical Nursing, 15(6), 685–695.
Arman, M., Rehnsfeldt, A., Lindholm, L., Hamrin, E., & Eriksson, K. (2004). Suffering related to health care: a study of breast cancer patients’ experiences. International Journal of Nursing Practice, 10(6), 248–256.
Cassel, E. J. (1982). The nature of suffering and the goals of medicine. The New England Journal of Medicine, 306(11), 639–645.
De Boer, M. F., McCormick, L. K., Pryun, J. F., Ryckman, R. M., & van den Borne, B. W. (1999). Physical and psychosocial correlates of head and neck cancer: a review of the literature. Ondaryngology—Head & Neck Surgery, 120(3), 427–436.
Edwards, D. (1998). Head and neck cancer services: views of patients, their families and professionals. British Journal of Oral and Maxillofacial Surgery, 36(2), 99–102.
Eriksson, K. (1992). The alleviation of suffering—the idea of caring. Scandinavian Journal of Caring Sciences, 6(2), 119–123.
Estabrooks, C. A., Field, P. A., & Morse, J. M. (1994). Aggregating qualitative findings: an approach to theory development. Qualitative Health Research, 4(4), 503–511.
Finnfeld, D. L. (2003). Metasynthesis: the state of the art—so far. Qualitative Health Research, 13(7), 893–904.
Fritz, D. J. (2001). Life experiences of head and neck cancer survivors: a pilot study. ORL-Head and Neck Nursing, 19(4), 9–13.
Gamble, K. (1998). Communication and information: the experience of radiotherapy patients. European Journal of Cancer Care, 7(3), 153–161.
SFS (1982). Hälsa- och Sjukvårdslagen HLS (the Health and Medical Services Act), p. 763. Stockholm: Riksdagen. (In Swedish)
Homs, M. Y., Kuipers, E. J., & Siersema, P. D. (2005). Palliative therapy. Journal of Surgical Oncology, 92(3), 246–256.
Jensen, L. A., & Allen, M. N. (1996). Meta-synthesis of qualitative findings. *Qualitative Health Research, 6*(4), 553–560.

Jones, A. (2001). A psychoanalytically informed conversation with a woman and her husband following major surgery for cancer of her neck and torso. *Journal of Advanced Nursing, 35*(3), 459–467.

Kahn, D. L., & Steeves, R. H. (1995). The significance of suffering in cancer care. *Seminars in Oncology Nursing, 11*(1), 9–16.

Kleinman, A. (1988). *The illness narratives: suffering, healing, and the human condition*. New York: Basic Books.

Kuuppelomaki, M., & Lauri, S. (1998). Cancer patients’ reported experiences of suffering. *Cancer Nursing, 21*(5), 364–369.

Larsson, M., Hedelin, B., & Athlin, E. (2003). Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. *Journal of Clinical Nursing, 12*(4), 562–570.

List, M. A., & Bilir, S. P. (2004a). Evaluations of quality of life and organ function. *Seminars in Oncology, 31*(6), 827–835.

List, M. A., & Bilir, S. P. (2004b). Functional outcomes in head and neck cancer. *Seminars in Radiation Oncology, 14*(2), 178–189.

Moore, R. J., Chamberlain, R. M., & Khuri, F. R. (2004). Communicating suffering in primary stage head and neck cancer. *European Journal of Cancer Care, 13*(1), 53–64.

Olsson, U., Bergbom, I., & Bosaeus, I. (2002a). Patients’ experiences of the recovery period 3 months after gastrectominal cancer surgery. *European Journal of Cancer Care, 11*(1), 51–60.

Olsson, U., Bergbom, I., & Bosaeus, I. (2002b). Patients’ experiences of their intake of food and fluid following gastric surgery due to tumor. *Gastroenterology Nursing, 25*(4), 146–153.

Paterson, B. L., Thorne, S. E., Canam, C., & Jillings, C. (2001). *Meta-study of qualitative health research: a practical guide to meta-analysis and meta-synthesis*. Thousand Oaks, Calif.: Sage.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3 ed.). London: Sage.

Richardson, A., Lee, L., & Birchall, M. (2002). Learning from patients with cancer and their spouses: a focus group study. *The Journal of Laryngology & Otology, 116*(12), 1028–1035.

Rydahl-Hansen, S. (2005). Hospitalized patients experienced suffering in life with incurable cancer. *Scandinavian Journal of Caring Sciences, 19*(3), 213–222.

Sandelowski, M., & Barroso, J. (2003). Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. *Research in Nursing & Health, 26*(2), 153–170.

SFS 1982:763. Hälso- och Sjukvårdslagen HSL (the Health and Medical Services Act) Stockholm: Riksdagen. (In Swedish)

Shaw, R. L., Booth, A., Sutton, A. J., Miller, T., Smith, J. A., Young, B., et al. (2004). Finding qualitative research: an evaluation of search strategies. *BMC Medical Research Methodology, 4*, 5.

Stern, P. N., & Harris, C. C. (1985). Women’s health and the self-care paradox: a model to guide self-care readiness. *Health Care Women Int, 6*(1–3), 151–163.

Thorne, S., Jensen, L., Kearney, M. H., Noblit, G., & Sandelowski, M. (2004). Qualitative metasynthesis: reflections on methodological orientation and ideological agenda. *Qualitative Health Research, 14*(10), 1342–1365.

Thorne, S., & Paterson, B. (1998). Shifting images of chronic illness. *Image: Journal of Nursing Scholarship, 30*(2), 173–178.

Thorne, S., Ternulf Nyhlin, K., & Paterson, B. L. (2000). Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies, 37*(4), 303–311.

Watt, E., & Whyte, F. (2003). The experience of dysphagia and its effect on the quality of life of patients with oesophageal cancer. *European Journal of Cancer Care, 12*(2), 183–193.

Wells, M. (1998). The hidden experience of radiotherapy to the head and neck: a qualitative study of patients after completion of treatment. *Journal of Advanced Nursing, 28*(4), 840–848.

Verschuur, E. M. L., Steyerberg, E. W., Kuijpers, E. J., Essink-Bot, M.-L., Tran, K. T. C., Van der Gast, A., et al. (2006). Experiences and expectations of patients after oesophageal cancer surgery: an explanatory study. *European Journal of Cancer Care, 15*(4), 324–332.

Winterling, J., Wasteson, E., Glimelius, B., Sjöden, P. O., & Nordin, K. (2004). Substantial changes in life: perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nursing, 27*(5), 381–388.

Yi, M., & Kahn, D. (2004). Experience of gastric cancer survivors and their spouses in Korea: secondary analysis. *Journal of Korean Academy of Nursing, 34*(4), 625–635.