Understanding Oral Cancer - A Lifeworld Approach

MARTA RÖING
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Abstract

Dental involvement with oral cancer patients during their treatment and rehabilitation can be long and intense. How can dental personnel better understand their role in the treatment of these patients? How does treatment affect the patients and their spouses? In searching for answers, the theories of phenomenography, phenomenology and hermeneutics are used to describe and interpret the experiences of the hospital dental treatment teams, oral cancer patients, and their spouses.

Study I reveals that hospital dental treatment teams perceive the encounter with head and neck cancer patients in three qualitatively different ways; as an act of caring, as a serious and responsible task, and as an overwhelming emotional situation, indicating that they are not always able to lean on education and professional training in dealing with situations with strong emotional impact. Study II gives insight into the lifeworld of oral cancer patients, and how the patient becomes embodied in a mouth that is increasingly ‘uncanny’, as it slowly ceases to function normally. Study III shows that oral cancer puts a hold on the lifeworld of the patients’ spouses which can be described as ‘living in a state of suspension’. These findings suggest that the support needs of patients and spouses appear to be greatest at treatment end, when, upon returning home, they are faced with the accumulated impact of the patients’ sickness and treatment. Study IV gives insight into what it may mean to live with the consequences of oral cancer, revealing a silent physical, emotional and existential struggle to adjust to a changed way of living.

This thesis raises the question if today’s organisation of oral cancer care can meet the varying emotional and existential needs of treatment teams, patients and spouses that were brought to light.

Keywords: Oral cancer, Dentistry, Lifeworld approach, Phenomenography, Phenomenology, Hermeneutics, Multiprofessional collaboration

Marta Röing, Department of Surgical Sciences, Akademiska sjukhuset, Uppsala University, SE-75185 Uppsala, Sweden

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This thesis is based on the following four papers, which will be referred to in the text by their respective Roman numerals:

I. Ways of understanding the encounter with head and neck cancer patients in the hospital dental team – a phenomenographic study.
Röing M, Hirsch J, Holmström I.

II. The uncanny mouth – a phenomenological approach to oral cancer.
Röing M, Hirsch J, Holmström I.

III. Living in a state of suspension – a phenomenological approach to the spouse’s experience of oral cancer.
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Artist’s Statement

“The Vessel, archetypal in its nature, has meaning to us all. We each have our own stories that could be expressed through an exploration of this form. This open bowl for me, is just such an exploration – a visual expression of this particular moment in my life.

Everything about this work; dimensions, the textures, the collaged materials, the painted circular shapes – hovering, forming, dissolving and reforming, all these things are chosen elements. Elements that I have brought together to form a mixed media artwork. The creation of the work is a finite process. The fact that there is a solid final end product, ironically, is the antithesis of some of the very ideas and thoughts that I am exploring here.

Everything is change. Nothing stands still. From one breath to the next I am transformed in the great and grand flow that permeates all aspects of my being”.

Cover picture by Canadian artist Janet Moore
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1. Preface

In 1989, I accepted a temporary appointment as a hospital dentist at the Uppsala University Hospital. In the course of my work there I entered the hospital world, and the treatment and care of patients undergoing radiation therapy for head and neck cancer, patients with hematological malignancies, bone-marrow transplants, patients undergoing heart, kidney, or liver transplants. I felt at the time that I had finally found an area of dentistry that truly interested me and that I wished to continue with. I was fortunate to be able to find temporary appointments in other clinics in Uppsala and Stockholm, and, over the years, I gained experience of dental care of a wide variety of medically, physically and/or mentally compromised patients, and patients with dental phobias.

While working with patients with dental phobia I realized I knew very little about why these people were so afraid, how their thoughts affected the way they felt and acted. I felt a need to learn even more – to try and obtain an even more complete picture of my patients. As a result I attended and completed a 2-year course in basic psychotherapy. This course changed my way of looking upon not just my patients, but fellow human beings as well. It helped me see other people as the individuals they are – it added a deeper dimension to my life.

I was again fortunate when, in 2001, I returned to the Uppsala University Hospital and resumed my involvement with the group of patients which had interested me the most from the very beginning – patients with head and neck cancers. Head and neck cancer is not only life-threatening, it can also affect an individuals’ appearance and basic functions such as eating, swallowing and speaking. Dental involvement with these patients during their hospital treatment is both long and intense, and I remember my own initial reactions and feelings of inadequacy, helplessness in being on the sidelines, witnessing their medical difficulties and trying to respond to their needs in a meaningful way. As I reflected on my own reactions, I began to wonder about my colleagues - how did they feel about our dental role in the care of these patients? The patients - how were they affected by their sickness and treatment? What about their wives or husbands? Did we really understand how they experienced their situations? What was important for them? Were we really helping them? Could we do more? This thesis is hence, searching for answers to these questions.
2. Introduction

Every year, approximately 700 people in Sweden are diagnosed with oral cancer \(^1\). The following is a description of one patient’s story. This story is true, although some details have been changed to assure confidentiality.

A healthy man in his mid-thirties was referred to the Department of Oral and Maxillofacial Surgery and Hospital Dentistry at a university hospital in Sweden by his family dentist for treatment of persistent pain and increasing swelling after extraction of a wisdom tooth in the upper right jaw. A diagnostic biopsy was taken, revealing squamous cell carcinoma, growing from the area where the tooth had been extracted, and extending to the maxillary sinus. The patient was immediately referred to medical specialists in head and neck surgery and oncology for further testing and treatment planning. It was decided that treatment would begin with chemotherapy, followed by preoperative radiation therapy and finally surgical removal of the upper right jaw.

At this time, the patient was referred to the hospital dental team for elimination of sources of infection in the mouth prior to chemotherapy and radiation therapy, and regular care and help in relief of the intra-oral side effects of chemotherapy and radiation therapy (which may be soreness and ulcerations in the lining of the mouth). The hospital dental team subsequently followed the patient during the two months of chemotherapy and the following radiation therapy.

After surgery they treated the patient in the ward and continued to help in care of the surgical defect. In due time the patient was able to come down to the hospital dental clinic to receive a specially designed temporary denture. This temporary denture had been constructed by using models of the patient’s teeth made before surgery and was meant to provide closure of the defect in the jaw after surgery to help the patient speak and eat. Yet surgery had left the patient with difficulties in opening his mouth. As a result, the patient continued to visit the hospital dental clinic during the next 6 months for care of his surgical defect, adjustment of his denture, and training in opening and closing his mouth.

A year after the initial cancer diagnosis, a new biopsy taken in the area of the defect in the upper jaw revealed cancer recurrence. Treatment was to begin again with chemotherapy, followed by brachytherapy (placement of radioactive implants directly into the tissue next to the cancer). Again, during the following 4 months of chemotherapy, the patient was referred to the
hospital dental team for care and relief of intra-oral side-effects of chemotherapy.

The side-effects of the following brachytherapy resulted in very severe soreness and ulcerations in the lining of the mouth, and increasing difficulties in speaking and eating. At this time the patient had extreme pain in opening his mouth and removing the temporary denture became almost impossible. Hospitalization became necessary to prevent dehydration and malnutrition and the hospital dental team was called on for help with the denture as well as care of the mouth. The patient underwent surgery of the right temporo-mandibular joint (jaw joint) in an attempt to increase his ability to open his mouth.

A month later, the patient was again back at the hospital with increasing facial pain. Clinical inspection revealed osteoradionecrosis (death of previously radiated bone) in the area of the surgical defect. The patient was referred to another hospital for hyperbaric oxygen therapy, a method where oxygen under pressure is intermittently inhaled in order to stimulate regrowth of blood vessels in damaged tissue and bone adjacent to areas treated by radiation therapy.

In spite of this treatment, the patient’s problems continued. As the defect increased in size due to osteoradionecrosis his temporary denture could not be adjusted to completely cover the surgical defect and difficulties in being understood arose. His pain was now chronic, and he experienced numbness of the right side of his face, and could not close his right eye. A new biopsy taken from the defect revealed recurrence of squamous cell carcinoma. Chemotherapy was again the treatment of choice, and again hospital dental teams were called on for care of his mouth. They continued helping the patient in caring for the steadily increasing defect in the mouth, until the patient’s death a year later, four years after initial diagnosis.

This patient’s story describes how complex the treatment of oral cancer can be. It also reveals the extent to which dental personnel can be involved in the care of oral cancer patients. Yet treatment is not always this complex, and does not always end in such an early death of the patient. While such extensive participation on the part of the dental treatment teams is not always required, the situation described is not unusual when treatment of large tumours has resulted in removal of parts of the maxilla or mandible. The mouth and the maxillofacial area is, after all, the only part of the body that is not under the primary care of medicine - it is the working domain of the dental profession.

This may make treatment of oral cancer unique, yet at the same time it may pose a problem for members of the dental treatment teams. Training in communication skills and cancer care is most often prioritized for medical and caring professionals, leaving dental personnel without specific basic training in the care of cancer patients.
How can members of the dental treatment teams better understand both the patients and their role in treatment of these patients? Searching for answers can begin in reviewing present literature on oral cancer, which is extensive.

As mentioned in the above story about a patient, treatment of oral cancer can include surgery, radiation therapy, chemotherapy, or a combination approach \(^4\)\(^{-6}\). Many research studies have used validated questionnaires to describe the quality of life of oral cancer patients during and after medical treatment \(^7\)\(^{-9}\). These studies have revealed that the long-term effects of radiation therapy may leave patients with symptoms such as dry mouth and altered taste and that surgery may result in difficulties in eating, swallowing, speaking, or facial disfigurement \(^8\)\(^{-12}\). In a similar manner, studies with a quantitative approach have revealed that families as well as patients are profoundly affected by cancer in the head and neck region, and that their concerns and degrees of distress differ across different time periods \(^13\)\(^{-15}\). Assessment of quality of life in this way has become both an important and recognized outcome measure in oral cancer treatment \(^8\). The general trend is that the quality of life may be lowest during treatment, then slowly recovers to pre-treatment levels after a year \(^16\). Even so, for the patients that survive, oral cancer treatment may have a persisting long-term adverse effect on their psychological and social functioning after end of treatment \(^8\)\(^,\)\(^11\).

Yet knowledge from these studies, although imperative, does not give the complete picture. These quantitative studies deal with the generalities of oral cancer treatment, they describe general symptoms and effects. They do not take into account the uniqueness of human beings, and as such, how unique the experience and understanding of oral cancer can be for each individual involved. It is this knowledge that may allow a more complete understanding of the disease.

Qualitative studies which focus solely on the perspective of the everyday life, thoughts, and feelings of oral cancer patients and their spouses are few \(^17\). While the contribution and participation of dental personnel in rehabilitation of oral cancer has been mentioned in literature \(^18\), there is little knowledge today devoted to how dental personnel experience their role in the treatment of these patients. Thus, this thesis was the search for answers to these questions.

**Aim**
The overall aim of this thesis is to describe the experience of oral cancer from the perspective of the dental treatment teams, the patients and their spouses.
Specific aims:
Study I. To describe the variation in ways a group of hospital dental teams experience and understand the encounter with head and neck cancer patients.

Study II. To describe how patients with oral cancer experience their sickness and treatment.

Study III. To describe oral cancer and its initial treatment as experienced by the patients’ spouses.

Study IV. To explore what it may mean to live with the consequences of oral cancer.

Outline of this thesis
Having given the aim of this thesis, I will start, in chapter 3, by presenting background facts about oral cancer and its treatment and rehabilitation. Then, I will introduce fundamental concepts in healthcare that can influence the care and treatment of oral cancer patients today. And finally, in this chapter, I will introduce the philosophical and theoretical background to researching the lived experiences of human beings.

Presentation of the studies begins in chapter 4 with an explanation of choice of methods, and a description of the setting and ethical considerations. Chapter 5 is a description of the experience of oral cancer from the perspective of hospital dental treatment teams. The following two chapters describe the feelings and thought of the patients (in chapter 6) and the spouses (chapter 7) during oral cancer treatment. Chapter 8 gives insight into what it is like to live with the consequences of oral cancer.

Chapter 9 starts with first, a discussion of the main findings and their implications for practice, followed by a discussion about methods, including the question of trustworthiness and preunderstanding in qualitative research. Conclusions are drawn in chapter 10, and finally, ideas for future research are presented in chapter 11.
3. Background

Oral Cancer

Understanding oral cancer begins with knowledge of the disease. In this section I will present facts and figures about oral cancer and descriptions of treatment and rehabilitation.

Facts

Head and neck cancer includes cancers of the oral cavity, pharynx and larynx. Internationally, the incidence of head and neck cancer varies. In industrialized countries it is the sixth most common form of cancer, behind lung, stomach, breast, colon and rectum, and cervix cancer. It is much more common in Brazil, where head and neck cancer represents 35% of all malignancies, and in certain parts of Southeast Asia.

Cancer of the oral cavity is most often squamous cell carcinoma. It is strongly related to behavioural and lifestyle factors such as tobacco, betel use and alcohol, and is preventable. Yet public awareness of oral cancer and its risk factors is minimal as compared, for example, to the well known contribution of tobacco use to the development of lung cancer. Poor diet, exposure to sunlight, chemicals and toxins are also possible risk factors. Certain virus infections, and chronic inflammation, as may be caused for example by poorly fitting dentures, have been implicated as risk factors as well.

The majority of patients with oral cancer in the industrialized world are individuals over middle age. Men are affected two to three times as often as women, largely due to their history of smoking and drinking. However, the incidence of tongue cancer appears to be increasing in younger age groups in some Western European countries. In Sweden, the incidence of oral cancer (cancers of the lip, tongue, and other parts of the mouth) is approximately 700 cases per year. The relative survival rate in Sweden is approximately 47.6% for men, and 49.2% for women, with tumour recurrence posing the greatest threat to long-term survival. Despite advances in treatment forms prognoses for these patients has not improved.

Cancer of the oral cavity may start as a sore in the mucous membranes that does not heal on the tongue, on the floor of the mouth, on the alveolar
process and on the lower lip $^{1,4,5}$. These early lesions are asymptomatic. As they increase in size symptoms such as difficulties in eating, swallowing and movement of the tongue may occur $^1$. Small lesions may be detected and diagnosed at early stages through visual inspection $^{1,6,22}$. Unfortunately, most oral cancers are detected at a late stage, requiring many months of treatment and rehabilitation $^{6,22}$.

**Staging of Oral Cancer**

Treatment varies depending on the stage of the disease at the time of diagnosis, and is planned according to the universal TNM system for describing the extent of cancer in a patient’s body $^{4,23}$. ‘T’ describes extent of the primary tumour, ‘N’ describes lymph node involvement, and ‘M’ describes the absence or presence of any distant metastases or spread of cancer to other tissues, bones or organs. Each component is measured on a scale from 0 to 4. Scores are first assigned to each of these 3 TNM components, then combined into stages of 1 to 4, to give a picture of the overall stage the cancer has reached $^4,23$.

In stage I, the oral tumour is smaller than 2 centimetres, and found only in the original site. With stage II oral cancers, the tumour is larger than 2 centimetres, but smaller than 4, and has not spread elsewhere in the body. Stage III tumours are at least 2 centimetres in size, and some lymph node involvement may be present. Finally, the stage IV tumours are extensive at the primary site, and invade adjacent structures such as bone, tongue, sinus, skin. They may have metastasized to other parts of the body, and lymph node involvement may be multiple $^4,23$. This clinical staging system is of value as well in predicting the prognosis for these patients. With increasing stage of oral cancer, the chance of long-term survival decreases $^{19,22}$.

**Treatment of oral cancer**

The treatment of oral cancer includes surgery, radiation therapy, chemotherapy, and combinations of these $^{4,6}$. Surgery and/or radiation therapy are the only curative treatment forms. The primary goal of treatment is survival, the secondary goal is reconstruction of function. Surgery to remove a small tumour in the mouth does not usually cause post treatment disfigurement or lasting problems.

Yet oral squamous cell carcinoma has the ability to spread locally into facial bone and muscle $^{24}$. As a result, surgical removal of larger tumours can mean removal of parts of the maxilla, mandible or tongue. These defects in the oral cavity left after surgery require reconstruction, as vital functions can be impaired $^{10,25}$. Partial removal of the maxilla may result in hypernasal speech, difficulties in chewing, fluid and food leakage, and facial disfigurement due to loss of midface bone $^{26}$. Difficulties in speech articulation, swallowing and disfigurement may arise after partial removal of the tongue or mandible $^{5,27}$.
Radiation therapy, used either pre- or postoperatively, requires daily treatments over a period of 6 weeks. For post-surgical patients starting radiation therapy, it may start while they are still recovering from the side effects of surgical treatment. Radiation therapy is painless, but does not remain so. Oral complications when the mouth is involved in the radiation field during radiation therapy can be both physically and psychologically trying for the patient. Mucositis, the thinning and eventual breakdown of oral mucosa can be very painful, and may result in difficulties in speaking, swallowing and taking in fluids. The patient may have to be hospitalized in order to prevent dehydration and malnutrition. Long-term effects of radiation therapy may include dryness of the mouth, rampant dental caries, difficulties in opening and closing the mouth due to extensive fibrosis and osteoradionecrosis, a radiation-induced non-healing wound in bone.

**Multidisciplinary team approach during treatment**

The treatment of oral cancer may thus consist of surgery and/or 6-8 weeks of radiation therapy, followed by reconstructive surgery and/or physical rehabilitation. It involves a large number of health care professionals, and is both complex and lengthy. During the initial hospital treatment period the patient meets medical and odontological teams in specialties such as head and neck surgery, plastic surgery and oral and maxillofacial surgery. Radiation therapy requires a specially trained team and consists of a radiation oncologist, physicist and radiation technologist. Speech therapists, nutritionists and occupational therapists play important roles in rehabilitation of speech and eating problems after partial removal of the tongue or floor of the mouth.

**Specific role of the odontological team**

The specific role of the odontological team may begin with the family dentist, who may discover cancer in the mouth during a routine dental examination. Then, in Sweden, hospital dental teams work together with dieticians and medical nursing staff in caring for these patients before, during and after surgery and radiation therapy. The role of the hospital dental staff before radiation therapy is elimination of sources of infection in the mouth and teeth and improving oral hygiene. During radiation therapy they provide patients with regular care, help in oral hygiene and relief for the effects of mucositis. At this stage they may meet these patients intensively for a period of up to eight weeks. Following treatment the regular family dentist takes over and continues to closely monitor the patients in order to minimize the long-term effects of radiotherapy as mentioned previously.

Specialists in oral and maxillofacial surgery may take part in the ablative procedure during initial surgical treatment. In addition, they may, together with specialists in prosthetics, become involved when surgical treatment of large tumours has resulted in defects in the maxilla or mandible.
fect in the maxilla is most often reconstructed with a prosthesis, or obturator. Specialists in prosthetics are responsible for construction, in the first place, of a temporary obturator, which is placed in a defect in the maxilla during surgery. This helps the patient to speak and swallow immediately after surgery and provides closure of the defect during the healing period. The final obturator is made three to five months later.

Reconstruction of a large tumour in the mandible is most often performed by grafting vascularized bone from the ilium or fibula at the time of tumour resection by oral & maxillofacial and microvascular surgeons. Osseointegrated dental implants can be placed in both maxilla and mandible either during tumour resection or at some appropriate time after to help retain dental prostheses. These advances in dental implant technology have dramatically changed the reconstruction of these defects and patients can now be provided with more reliable means of retaining prostheses.

This section has revealed the possible causal agents of oral cancer, and how oral cancer can be diagnosed, its clinical course, and treatment. In a sense, it has shown oral cancer as it may be seen through the eyes of treatment teams using the predominant medical model of the 20th century, biomedicine. In this model, the doctor or caregiver is supposed to be benevolent and paternalistic and the patient should be passive and grateful. The doctor follows the course of the disease, which is considered to be separate from the patient, in a detached and neutral manner. However, new models and concepts have entered the scene of healthcare, and will be discussed in the following section.

Factors of influence in the service of healthcare

In the section that follows I will introduce three current strong trends that have an influence on the service of healthcare today, namely evidence-based medicine, patient-centeredness, and holistic care, and what effect they may have in the treatment of oral cancer.

Evidence-based medicine

Evidence-based medicine (EBM) and clinical practice guidelines have influenced health policies and patient treatment since the 1990’s. EBM focuses on giving doctors the best available clinical expertise, scientific evidence and most effective treatment recommendations in making decisions about the care of individual patients. EBM is regarded to be both doctor-centered and disease-oriented, as it is the responsibility of the doctor to interpret scientific evidence of diseases derived mostly from randomised-controlled trials and systematic reviews.

The concept of EBM can be further clarified by reduction to five fundamental parts:
1. Clinical decisions should be based on the best available scientific evidence.
2. The clinical problem determines the evidence to be sought.
3. Identifying the best evidence involves epidemiological and biostatistical ways of thinking.
4. Conclusions based on the available evidence are useful only if put into action for individual patients or for population health care decisions.
5. Performance should be constantly evaluated.

As the above clearly illustrates, EBM has a positivistic, biomedical approach to health care. On the surface, this approach may seem vital to treatment outcome, yet it is criticized by many. It does not appear to leave any room for each patient’s individual knowledge and experience of their illness. Critics state that using EBM in providing better outcomes for patients is difficult to prove empirically. They question how often it is used by healthcare professionals, as the process of practising EBM, especially the technical search for literature, is considered to be difficult.

Furthermore, many clinicians hesitate to apply results from randomised control trials to their individual patients. While they accept that the trials are valid internally, in that they are designed to eliminate bias, they doubt that the results are externally valid. In other words, that the results of these trials can be generalized and applied to another group of patients.

Strauss and Sackett (1999) described how applying evidence to the individual cancer patient can be complicated by the life-threatening aspect of cancer. In the first place finding valid scientific evidence may not be easy. Then there may be difficulties in deciding if evidence from randomised control trials can be applied to the patient. The patient’s risk of death may increase if he or she has a more advanced disease than those included in the scientific evidence. Although the patient described by Strauss and Sackett had lung cancer, this situation may be just as true for patients with oral cancer.

Realizing the shortcomings of EBM, healthcare professionals have increasingly advocated a more ‘patient-centered’ consulting style.

**Patient-centeredness**
Most physicians and other caregivers agree that taking into consideration patients’ experiences and needs in making treatment decisions is important. Yet the understanding of the concept of patient-centeredness appears to differ. That is why a review of literature on patient-centeredness by Mead and Bower (2002) revealed no clear definition. Even so, this literature review resulted in defining five distinct dimensions of ‘patient-centered care’.
1. The biopsychosocial perspective - a perspective on illness that includes consideration of social and psychological (as well as biomedical) factors.
2. The `patient-as-person´ - understanding the personal meaning of the illness for each individual patient.
3. Sharing power and responsibility - sensitivity to patient’s preferences for information and shared decision-making and responding appropriately to these.
4. The therapeutic alliance - developing common therapeutic goals and enhancing the personal bond between doctor and patient.
5. The `doctor-as-person´ - awareness of the influence of the personal qualities and subjectivity of the doctor on the practice of medicine.

Stewart (2000) described 6 interactive components of patient-centeredness in her study on the benefits of patient-centeredness in a family practice. Here the physician aims at exploring the patient’s disease and illness experience. The experience of illness includes the patients’ feelings about being ill, their own ideas about their illness, how the illness affects their daily functioning, and their own ideas about treatment. Thereafter, the physician aims at understanding the whole person, finding common ground with the patient regarding treatment, recommending prevention and health promotion, and enhancing the patient-doctor relationship. The final component requires that patient-centeredness be realistic, in the sense that it is adapted to the patient’s condition.

Mead and Bowers’ clarification introduces the fact that the doctor is also a human being while the components described by Stewart dwell deeper into the patients’ experiences and feelings. These are just two examples as to how the concept of patient-centeredness can differ. Yet the core of patient-centeredness appears to be a humanistic biopsychosocial approach to health care.

What are the implications of patient-centeredness? How do the patients benefit? Most research literature reveals that patient centeredness can improve patient satisfaction and patients’ health status. It can increase the efficiency of care, and even patient compliance, as in control of diabetes and hypertension. In summary, this approach has a positive influence on the quality of care, and yet requires, in the first hand, good communication between doctor and patient.

Patient-centeredness and communication are especially important in the treatment of life-threatening diseases such as cancer. Here, it is vital for the physician and members of treatment teams not to ignore the patient’s experience of illness, which may include probable fears associated with cancer. Information from the physician about side-effects of treatment and prognosis can help in decreasing uncertainty and lessen patient anxiety.

Generally speaking, the majority of cancer patients (around 87%) want all possible information about their illness, as shown by a recent multi-centered study.
study in the UK. The patients in that study wanted first of all to be told the truth about their illness, if it was cancer, and their chances of survival. They had a desire to understand their illness and symptoms, and participate in treatment decisions. Good communication between doctor and patient may be the most important component of patient-centered care in the treatment of cancer.

**What about patient-centeredness in dentistry?**

In the past, dentists, like most other healthcare professionals, have had a paternalistic relationship with their patients. Patients sat in the dental chair with open mouths and dared not question the dentists’ authority and treatment plans. Patient-centeredness has entered the world of dentistry, and today’s dental patients expect information about health care choices and wish as well to be involved in the treatment decision. How well they are willing to accept and participate in treatment depends very much on the dentist’s ability to relate to them as the individuals they are.

There are many situational differences between dental and medical patients. One of the goals of patient-centeredness in both dentistry and medicine is patient satisfaction, yet patient satisfaction may include a different meaning in dentistry. Patients visit doctors and dentists on their own free will. The medical patient comes often only in times of illness, while the dental patient, in Sweden, comes most often regularly, once a year for example, for both treatment and prevention of oral problems. A patient that is not satisfied with their dentist does not come back. Some dentists have realized that patient satisfaction also makes good business sense, and invest in patient satisfaction measures such as modern practice facilities as well as high standard of care.

Dental treatment is disliked and feared by many patients, and a major concern for many dentists is the issue of how difficult or easy it will be for them to treat the patient. Paying attention to patients’ anxieties may play a major role in communicating with the patient. Another important component in communication with the patient aims at patient motivation and instruction, as prognosis and prevention of dental disease is highly dependant on patient compliance.

The situation changes for the dentist when the patient in the dental chair has dental phobia, or serious medical problems, or a life-threatening illness such as cancer. The demands on the dentist increase, and include seeing the whole patient, and the patient’s situation, not only the dental treatment. How equipped are dental personnel in responding to the needs of these patients and their families? How patient-centered are they then?
centeredness does not meet all the needs a patient may have? Can holistic care meet other needs?

**Holistic care**

While patient-centeredness, in research literature, appears to focus on the meeting between physician and patient, holistic care is most often associated with nursing. The PubMed database defines the MeSH-term ‘holistic nursing’ as follows 58: “A philosophy of nursing practice that takes into account total patient care, considering the physical, emotional, social, economic and spiritual needs of patients, their response to their illnesses, and the effect of illness on patients abilities to meet self-care needs”.

A phenomenographic study by Dahlberg (1992), revealed three following ways that holistic perspective on caring could be understood by nurses and teachers 59. First, it can be understood as taking into consideration all the needs of the individual undergoing care: medical, psychological, sociological and spiritual. The perspective is not holistic if one aspect is neglected 59. Secondly, it can mean looking upon the patient as the unique human being he or she is. Seeing the ‘whole’ person in this way allows an understanding of the patient’s point of view 59. Finally, it can mean regarding the patient and the caregiver together as the whole, bound together by their relation to one an other. The caregiver follows the patient during treatment, sees and understands the patient’s needs, and offers support and comfort. Inner strength and self-knowledge is required of the caregiver when working closely with a patient in this way 59.

The results of Dahlberg’s (1992) study are supported by the above mentioned definition, but go one step further. They highlight the special relationship between nurse and patient that can be meaningful to both, as the relationship may affect the thoughts and feelings of the caregiver as well as the patient 59 60. This, and the notion of the caregiver looking upon each patient as the unique human being he or she is, appears to be central to holistic caring.

Holistic care and patient-centeredness appear to have much in common. For both, ‘seeing the patient as a person’, and enhancing the relationship between patient and caregiver or doctor is important. Furthermore, taking into consideration the physical, psychological, social and spiritual dimensions is very similar to the biopsychosocial perspective mentioned in patient-centered caring.

Yet patient-centered care does not address the spiritual needs of the patient, and is not built upon a special bond between caregiver and patient. In my view, these two components of holistic caring are of special value to patients with life-threatening illnesses such as cancer. Holistic caring in cancer can offer patients encouragement, compassion, and ongoing support in their battle against the disease 61. While the responsibility of holistic care is
most often assigned to nurses, the concept of is very much alive among doc-
tors and other caregivers. How we can better see the `whole´ person and understand the world from his or her perspective will be discussed in the next section.

**Lifeworld research approaches**

Each human being experiences and understands their everyday world in a unique way, and takes this world for granted, without reflection. This world, in philosophical terms, is called the `lifeworld´ and is the everyday life, thoughts and feelings of human beings.

Knowledge of oral cancer, its’ possible causal agents, diagnosis, clinical course and treatment has previously been described in the Introduction and Background. Most of this knowledge has been acquired by use of `scientific or quantitative methods´, which focus on objectivity, quantification of data, and description of results in statistical terms. And yet a different method is required for understanding the effect this background knowledge of oral cancer may have on the patients and other individuals involved. The focus of investigation is now the `lifeworld´ of human beings and understanding the meaning of their lived experiences. This lends itself to a qualitative approach which focuses on human experience and subjectivity rather than objectivity.

In this section I will introduce the theoretical background to phenomenography, phenomenology, and hermeneutics. The purpose now is to describe how these research approaches are the tools with which one can explore, describe and understand the lifeworld of human beings.

**Phenomenography**

Phenomenography does not have its base in philosophy. Instead, it is a recent qualitative research approach which studies the variations in ways that people in a group understand phenomena in the world around them. It was first developed within an educational framework in Sweden about 30 years ago. According to the founder, Ference Marton, it aims at “description, and analysis and understanding of experiences, as phenomena, aspects of reality are experienced in a relatively limited number of qualitatively different ways.” These qualitatively different ways are not to be seen as individual qualities, and neither should they be considered as categories for classifying individuals.

In phenomenography, the most common method of gathering data is in-depth interviews, where the informants are given an opportunity to describe their ways of understanding the phenomenon in question. About 20 informants are needed to reach a point of saturation in capturing all the possible variations. The aim of interview analysis is to identify the different ways of understanding and classify them under categories of description.
describing the results of a phenomenographic study, these categories of description are then presented in an `outcome space´ in such a way as to suggest the order and relation which the different categories have to each other 66.

**Phenomenology**

Literally, phenomenology is the study of phenomena 64. Phenomenology as a philosophical tradition was launched by the German philosopher Edmund Husserl (1859-1938). It has subsequently developed into a research approach which focuses on a person’s immediate lived experience of a phenomenon and assumes that experiences of different people have core meanings or essences that can be mutually understood 71. Data is most often gathered by interviewing people who have directly experienced the phenomenon in question 71.

For Husserl, our everyday world, the world that exists without our thinking about it, and that we experience the way it is, in its `natural´ attitude, is our `lifeworld´ 64 72 73. He believed that the central way we experience phenomena in our lifeworld is through our consciousness, and that this conscious experience is always intentional, directed towards something 63 64 72 73. He believed as well in the notion of transcendentality, claiming that we can separate parts of our everyday experience of living from our consciousness 63 64 72 73.

For Husserl phenomenology was the means by which a scientist could search for and describe the essences, or essential nature of our conscious experiences of phenomena in our lifeworld 63. Since this lifeworld, in its natural attitude, is lived before it is reflected upon, it is not easily accessible. Therefore, gaining knowledge of the lifeworld, using the phenomenology of Husserl, starts with studying what our consciousness is directed towards. As an example, we always think about something, perceive something or remember something. In philosophical terms, this is called intentionality 63 64 72 73.

Furthermore, Husserl believed that in searching for essences, it is necessary to be open-minded and put aside or bracket out our familiar way of thinking about the world, or what is called the our `natural attitude´. Husserl called this the practice of epoché 64 73 74. This shift from a natural to “phenomenological” attitude, also referred to as phenomenological reduction, allows identification and description of a phenomenon in its pure form 64 73 74. Husserl’s phenomenology, therefore, when used as a research approach, is often regarded to be descriptive phenomenology 64.

The German philosopher Martin Heidegger (1889-1976), as a student of Husserl, accepted Husserl’s thoughts on the lifeworld, but reacted against Husserl’s thoughts on pure consciousness 75. He argued that consciousness could not be separated from the world of lived experience, since, in our everyday existence, we are always a part of the world. In his book, *Being and*
Time, Heidegger discussed the many aspects of human existence by studying the average everyday way we are in the world. As such, consciousness, for Heidegger, was only one way that we are in the world. He introduced the concept of Da-sein, or Being, which can refer to the being-in-the-world of a single person or the general being-there of human existence. In existing as Da-sein, according to Heidegger, one is aware of one’s own Being and mortality, and also that one is always with others. With Heidegger, the life-world became more worldly, a `being-in-the-world.

Since we are already in the world, Heidegger’s phenomenology recognizes that knowledge must be gained from within, from the way we interpret our being-in-the-world. We cannot put the world aside, or bracket it, and neither can we bracket our pre-understanding of the world. Heidegger’s phenomenology focuses on our interpretation of being-in-the-world, and on our pre-understanding of it. As a research approach, then, Heidegger’s phenomenology is regarded to be an interpretive phenomenology.

The French philosopher Maurice Merleau-Ponty (1908-1961) introduced the experience of the lived body to phenomenology. For Merleau-Ponty, each human being does not just have a body, but is the body. Since we both experience and have access to our lifeworld through our bodies, our consciousness, therefore, is embodied. Each human being, in being embodied, has therefore their own unique relationship to space, time and each other. Thus the phenomenology of Merleau-Ponty includes the lived experience of the body, space, time and relations.

**Hermeneutics**

Hermeneutics is defined in the Cambridge Dictionary of Philosophy as “the art or theory of interpretation, as well as the type of philosophy that starts with questions of interpretation.” Hans-Georg Gadamer (1900-2002) is regarded to be the leading proponent of modern hermeneutics. As a pupil of Heidegger, he developed on Heidegger’s notion of understanding based on interpretation. In his book *Truth and Method* he investigated the nature of understanding. For Gadamer, language was the medium of being in the world and through which one understood and interpreted the world. He maintained that our consciousness was strongly influenced by our history and tradition. Because of this, our understanding occurred from a particular “horizon”, or point of view, determined by our history. Our understanding could also be either positively or negatively prejudiced by our traditional background. As such, Gadamer believed that interpretation, either of texts or dialogue, involved becoming aware of our prejudices and being open to the horizons of understanding of the past, or others. Interpretation evolved then as a “fusion of these horizons.”

It can be said that Gadamer broadened Husserl’s thoughts on the need to bracket preunderstandings by explaining what the term meant and what it was based upon. Accordingly, when applying the hermeneutics of Gadamer
in the search for knowledge of the lifeworld, we have an opportunity to reach a new understanding if we know where to look for our prejudices or preunderstandings.

The French philosopher Paul Ricoeur (1913-2005) was also influenced by the phenomenologies of Husserl and Heidegger. For Ricoeur, the primary aim of hermeneutics was interpretation of not only texts, but human actions and situations as well. He believed that texts may have many meanings, and that interpretation of texts involved trying to understand these meanings. In his book Interpretation Theory (1976) he developed a method of interpretation. In this method, the preliminary reading of a text involved guessing the author’s meaning. Then, in order to try and explain what the text said, it was necessary to create at distance between the reader and the text. This was achieved by objectifying the text, or putting focus on the text by itself, and the way it was constructed. Interpretation then evolved as a result of the back-and-forth movement between the preliminary unreflected understanding and, with text explanation as a go-between, a more reflected understanding of the text.

The implications of Ricoeur’s hermeneutics are that when lived experiences are narrated during research interviews, speech becomes fixated as text. Ricoeur’s theory of interpretation gives researchers the means by which the multiple meanings in a text can be understood and interpreted.

In summary, there are many research approaches which can be applied in the search for knowledge and understanding of the lifeworld of human beings. In this thesis, these three research approaches were used in searching for an understanding of oral cancer. Why and how they were used is presented in the next chapter.
4. Introduction to Studies I-IV

Methods
Each of the methods chosen in this thesis had a specific purpose. Phenomenography was chosen as the research method for study I, as the purpose of the study was to describe the variation in ways a group of hospital dental teams can understand their encounter with head and neck cancer patients. The purpose of studies II and III was to describe how the patients (in study II) and spouses (in study III) experienced oral cancer. Phenomenography focuses on ways of understanding, and as such has limited value in exploring and describing peoples’ subjective experiences of phenomena. Phenomenology was therefore chosen as research method in these two studies as a means of gaining access to the lifeworlds of the patients and spouses. Study IV aimed to probe deeper, namely what the experience of oral cancer could mean to individuals involved. Consequently, a hermeneutic approach was used in study IV to explore and interpret what it may mean to live with the consequences of oral cancer.

Setting
The setting for studies I, II, III and IV was a clinic for oral and maxillofacial surgery and hospital dentistry in a university hospital in Sweden. In this hospital a multidisciplinary treatment approach had been established between medical specialities (Oncology, Plastic Surgery, Ear, Nose & Throat Diseases) and dental specialities (Oral and Maxillo-facial Surgery, Oral Prosthetics and Hospital Dentistry). Since the university hospital works together with four smaller hospitals in nearby counties, the patients treated for head and neck cancer were among the two million inhabitants in the catchment area of the hospital.

Ethical Considerations
Ethical regulations and guidelines according to the Swedish law 2003:460 were followed in study I. The interviewees were contacted personally and agreed to participate after being informed of the aims, methods and anticipated benefits of the study. They were guaranteed confidentiality and informed that they were at liberty to abstain from participating, and were free as well to withdraw from the study at any time.
Studies II, III and IV were approved by the Ethics Committee at the Faculty of Medicine, Uppsala University, Dnr 02-105. The interviewees had been contacted personally by me, and had agreed to participate after being informed of the aims, methods and anticipated benefits of the study. They were guaranteed confidentiality and informed as well that they were at liberty to abstain from participating and were free to withdraw from the study at any time. As the questions asked involved personal and emotional experiences every interview was rounded off by asking how the interviewees experienced the interview and questions asked. This gave them an opportunity to reflect on their answers and deal with any unexpected thoughts and worries that might have been awakened during the interview.

Overview

Table 1. Aims, participants and analytical approaches used in Studies I-IV

<table>
<thead>
<tr>
<th>STUDY</th>
<th>SPECIFIC AIM</th>
<th>DATA COLLECTION</th>
<th>ANALYTICAL APPROACHES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I</td>
<td>To describe the variation in ways a group of hospital dental teams experience and understand the encounter with head and neck cancer patients.</td>
<td>Purposeful sample of interviews with 20 members of hospital dental teams.</td>
<td>Phenomenography</td>
</tr>
<tr>
<td>Study II</td>
<td>To describe how patients with oral cancer experience their sickness and treatment.</td>
<td>Purposeful sample of interviews with seven oral cancer patients.</td>
<td>Existential phenomenology</td>
</tr>
<tr>
<td>Study III</td>
<td>To describe oral cancer and its’ initial treatment as experienced by the patients’ spouses.</td>
<td>Purposeful sample of interviews with seven oral cancer patients’ spouses.</td>
<td>Existential phenomenology</td>
</tr>
<tr>
<td>Study IV</td>
<td>To explore what it may mean to live with the consequences of oral cancer.</td>
<td>Purposeful sample of interviews with five oral cancer patients.</td>
<td>Hermeneutics</td>
</tr>
</tbody>
</table>
5. Professionals’ perspectives – Study I

Little is known about how dental personnel experience and understand their encounter with cancer patients.

Participants
Study I is based on interviews with twenty members of hospital dental teams, eight dentists, (six female, two male), six dental hygienists (all female), and six dental nurses (all female), working in a city in mid-Sweden and the nearby counties. Purposeful sampling was used, as the aim of the study was to sample a group of people, in this case hospital dental teams, in a setting not so common for dental personnel, the treatment of head and neck cancer patients in a hospital. Only hospital dental personnel with experience of working with patients with head and neck cancer were selected and asked to participate. The dental personnel are described in table 2.

Data Collection
The participants were interviewed at their place of work. The interviews were open-ended with focus on their experiences of the encounter with head and neck cancer patients. They sought answers to the following three questions: 1) How do you feel when you meet a patient with head and neck cancer? 2) How do you cope with your feelings? 3) How did you experience the interview and questions asked? Follow-up and probing questions were then used to encourage as detailed and spontaneous descriptions of the experiences as possible.

Data analysis
Phenomenographic analysis was performed. Data was analysed in a step-wise manner according to Dahlgren and Fallsberg. The most significant statements where the person interviewed described feelings and thoughts connected to the encounter with the patient were identified, and then compared with each other. These were grouped under three aspects of the encounter, namely: what the encounter requires/demands, what the encounter means/gives and what feelings/thoughts are aroused during the encounter. A preliminary description of the way the encounter was understood was made, and labelled, for each interview. Comparing these labelled ways of understanding with each other, looking for similarities and differences among all the interviews identified that the encounter was understood in three qualita-
tively different ways. These were labelled and described under different categories of description. Finally, these categories of description were presented in an `outcome space´ in such a way as to suggest the order and relation the different categories had to each other.

Table 2. Descriptive characteristics of informants (N = 20)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
</tr>
<tr>
<td>Female</td>
<td>18</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>31-40</td>
<td>4</td>
</tr>
<tr>
<td>41-50</td>
<td>7</td>
</tr>
<tr>
<td>51-60</td>
<td>9</td>
</tr>
<tr>
<td>Profession</td>
<td></td>
</tr>
<tr>
<td>Dentist</td>
<td>8</td>
</tr>
<tr>
<td>Dental Hygienist</td>
<td>6</td>
</tr>
<tr>
<td>Dental Assistant</td>
<td>6</td>
</tr>
<tr>
<td>Years of experience with head and neck cancer patients in hospital dentistry</td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>8</td>
</tr>
<tr>
<td>6-10</td>
<td>5</td>
</tr>
<tr>
<td>11-15</td>
<td>5</td>
</tr>
<tr>
<td>16-20</td>
<td>2</td>
</tr>
</tbody>
</table>

Findings
Three qualitatively different ways of understanding the encounter with head and neck cancer patients were identified. These were labelled and described under three categories of description as follows; A) The encounter is perceived as an act of caring; B) The encounter is perceived as a serious and responsible task; C) The encounter is perceived as an overwhelming emotional situation (Figure 1).

Category A – The encounter was perceived as an act of caring
In the first category the encounter was perceived as a rewarding opportunity to aid a fellow human being struggling with a life-threatening disease. Focus was on interacting with and supporting the patient throughout the treatment. With help from past personal experiences these dental staff members were
able to handle strong feelings and add a new dimension to their “dental” role as they entered into a caring partnership with the patient. The encounter allowed some to gain insight in how to cope with their own mortality.

**Category B - The encounter was perceived as a serious and responsible task**

In category B the focus of the encounter was the patient’s treatment, either medical or dental. A need to seek knowledge and continuing education was important. Acting professionally, as well as distancing tactics, was emphasized in this way of understanding. Difficulties described were treatment-related. The dental staff experienced conflicting emotions with the knowledge that the patient may have to undergo dental treatment (most often extraction of teeth) before beginning radiotherapy. There were feelings of sympathy for the patient, and worries that dental treatment would add to the patients’ already heavy burden of having cancer.

**Category C – The encounter was perceived as an overwhelming emotional situation**

In category C, meeting a patient with life-threatening cancer was perceived as a confrontation with death and personal mortality. The patients were observed and followed with great interest, admiration, and sympathy, although from a distance. Identification with the patient dominated, arousing strong feelings of anxiety. These strong emotions did not allow many of the staff to fully escape from their work. The informants expressed a need to discuss and air their emotional responses to difficult situations. With no outside help, they sought support among each other.

Over time some perceived themselves as more experienced and felt more confident in their ability to “leave their feelings and thoughts at work”. Others expressed a need for professional counselling and guidance. Conflicting feelings regarding the patients’ treatment, ‘forbidden’ thoughts doubting the patients’ chances of survival were revealed. Other difficult situations described were feelings of inadequacy when communicating with patients, and feelings of ethical distress when ‘put on the spot’ by questions from patients about their medical treatment.
Figure 1. The three categories of description of ways of understanding the encounter with head and neck cancer patients among hospital dental personnel.

**Category A**

*Encounter is perceived as an act of caring*

*Focus on patient as individual*

"The patient hasn’t given up hope and we haven’t given up hope and no one has. We just keep on trying to help as fellow human beings and treat them with as much dignity as possible... all the time."

(Dental staff 1)

---

**Category B**

*Encounter is perceived as a serious and responsible task*

*Focus on treatment*

"I believe that I can distance myself and at the same time feel compassion for the patient and I think I do just that. I try to think professionally, that’s all.... of course I realize sometimes that the prognosis for a certain patient is not so good but I don’t usually go in that deeply."

(Dental staff 4)

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**Category C**

*Encounter is perceived as an overwhelming emotional situation*

*Focus on patient’s life-threatening cancer*

"Then right away I think... maybe the tongue is gone, half of it or all of it... I think that... this is just not going to work out... and the way to the end will be unbelievably difficult... that’s how it feels."

(Dental staff 11)
6. Patients’ perspectives - Study II

Method
The method used in gaining a better understanding of the lived experience of oral cancer patients in study II, existential phenomenology, is based on the philosophies of Husserl and Merleau-Ponty and further developed as a research approach by van Manen. Van Manen’s method aims to describe how phenomena present themselves in accounts of the four fundamental structures or existentials by which all human beings experience the world, through their subjective lived experience of body, human relations, space, and time. Lived body refers to physical and bodily presence. Lived relationality is the lived relation human beings maintain with others. Lived space can be felt, and affects the way human beings feel, and lived time is a human beings’ temporal way of being in the world.

Participants
Study II is based on a purposeful sample of interviews with seven patients, 3 men and 4 women, ranging in age from 45 years to 78 years, (median age 62 years), who had been treated at the hospital for cancer in the oral cavity. Primary cancer diagnoses were floor of mouth (n=3), tongue (n=1), maxilla (n=2), and gingiva (n=1). All had undergone radiation therapy. For five patients, where surgical treatment was indicated as well, surgery had resulted in large intra-oral defects which required reconstruction of either the maxilla (n=3), mandible (n=1) or tongue (n=1). These intra-oral defects were not visible, yet had resulted in difficulties in speech, eating, and swallowing. Reconstruction of the mouth was still in progress for two of these patients at the time of interview.

Data Collection
Interviews with the patients were arranged to coincide with appointments they had at the hospital for either post-treatment check-ups, treatment of complications or recurrence, or rehabilitation. These interviews included five main open-ended questions: 1) How do you feel when you think about your sickness and treatment? 2) How do you cope with your feelings? 3) How would you describe your life today? 4) How do you feel about the future? 5) How did you experience the interview and questions asked? Follow-up and probing questions were used to encourage as detailed and spontaneous de-
scriptions as possible. The interviews ranged in length from 45 to 75 minutes.

**Data analysis**

Guided existential reflection as described by van Manen was then used in analysing the data. Each interview text was divided into “sentence clusters” and grouped under four categories, the four fundamental existentials. The “sentence clusters” were then transformed from the patient’s spoken language into descriptions of their experience of lived body, relation, space and time. The transformed descriptions were summarized and structured, preliminary themes were identified in each interview. The themes of all the interviews were then compared and combined to give a general structure of the phenomenon. Reflection upon the general structure as a whole allowed formulation of a description of the lifeworld of oral cancer patients during treatment.

**Findings**

The lifeworld of the patients changed drastically during treatment. The central theme that emerged was the patient’s embodiment in a mouth that slowly became ‘uncanny’, or unreal. The changing character of the patients’ lifeworld could be viewed through the patients’ experiences of lived body, relation, space and time at diagnosis and treatment start, during treatment, and treatment end (table 3).

**Experiences at diagnosis and treatment start**

Cancer in the mouth could mean living with a growing swelling in the mouth, realizing that something was wrong, yet hoping that it was just an infection. Yet hearing the doctors’ suspicions of cancer, receiving a direct referral to the specialists, had an overwhelming impact. Initially, the meaning of lived time altered. It became precious for the patients as they were referred on to the hospital for further testing and treatment planning. Their life situations were suddenly threatened by death, and immediate treatment was imperative.

The patients’ perception of self was also affected at this time, as they became individuals facing cancer, a ‘patient’. Their experience of lived relation had been transformed into a situation of dependency on doctors and treatment staff. Their spatial lifeworld had been abruptly moved from the safe home and security of normal living and work to unfamiliar hospital staff and surroundings.

**Experiences during treatment**

The impact of cancer treatment on the body was unexpected. For some patients, feelings before and after surgery were positive. Surgery meant removal of the tumour and a fast recovery, and time seemed to move faster
than normal. Yet surgery may have left a hole in the upper jaw, or half a tongue. Fluids could leak from the mouth or nose when drinking, difficulties in speech and being understood arose. Very few patients were prepared for the following six to eight week long radiation therapy. The patients’ experience of lived space became restricted as they were required to adjust to daily radiation treatments and living by the clock. As the side-effects of radiation therapy accumulated, the mouth became drier and drier, increasingly painful, and eating and swallowing became all the more difficult. The mouth slowly ceased to function normally for some patients, and their lives had to be supported by feeding tubes through the nose.

As treatment progressed, care and understanding from doctors and hospital treatment staff was deeply appreciated. Time seemed to slow down as radiation treatment came to an end. The body, slowly overcome by an overwhelming tiredness, brought with it a decreasing power to resist negative thoughts, feelings of self-pity, anxiety, and hopelessness.

**Experiences at treatment end**

Coming home directly after radiation therapy, the patients faced the reality of a changed mouth that had not yet recovered from initial treatment and did not function normally. These problems restricted the patients’ lived space at home. Loss of appetite, taste, difficulties in swallowing meant worry about nourishment and eating in the presence of others. Difficulties in speech after surgery hampered their desire to return to normal social activities.

Understanding from friends was needed when eating socially, as drooling occurred, or liquids came from the nose when drinking. The meaning of time and lived space were changed. Habits that were once pleasurable, routines that were once taken for granted acquired new meanings. The idea of travelling seemed difficult and unappealing. Adjustments in living routines at this time meant learning to chew differently, a changed diet, or bringing own food to social events.

Thoughts about the future were at this time both optimistic and pessimistic. The desire to regain normal functions in the mouth had become the focus of attention, and the patients looked forward to rehabilitation. Thoughts of cancer recurrence were ever present.
Findings – Descriptions of oral cancer patients’ lived experiences of body, relation, space and time.

<table>
<thead>
<tr>
<th>PHASE OF TREATMENT</th>
<th>LIVED BODY</th>
<th>LIVED RELATIONS</th>
<th>LIVED SPACE</th>
<th>LIVED TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment start</td>
<td>Body taken over by cancer, out of control, treatment imperative – as cancer is life-threatening</td>
<td>Changed perception of self. Situation of dependency on doctors.</td>
<td>Patient moves from safe home and security of normal living to unfamiliar hospital surroundings.</td>
<td>Sense of time altered - time becomes precious.</td>
</tr>
<tr>
<td>During treatment</td>
<td>Focus of attention turns to mouth and awareness of increasing pain and dysfunction as treatment progresses. Mouth is inescapable, felt with every attempt to speak, eat and swallow.</td>
<td>Families reach out to each other. Care and understanding from hospital staff becomes all more appreciated.</td>
<td>Adjustment to hospital world and routines of treatment.</td>
<td>Appears to move faster than normal at beginning of treatment. Seems to slow down during 6-8 week long radiation therapy.</td>
</tr>
<tr>
<td>End of initial treatment</td>
<td>Mouth has ceased to function normally. Patients have become embodied in a mouth that is perceived as uncanny. Rehabilitation of mouth is focus of attention.</td>
<td>Need for care and understanding appears to continue upon coming home.</td>
<td>Lived space restricted at home, socially due to difficulties in eating, speaking.</td>
<td>Meaning of time altered. Hope for a future.</td>
</tr>
</tbody>
</table>
7. Spouses’ perspectives – Study III

Method
The purpose of study III was to gain a better understanding of the lived experience of oral cancer patients’ spouses during their partners’ treatment. For that reason, the method used in study III is the same method used in study II, with in-depth interviews analysed by van Manen’s guided existential reflection. This method, as already mentioned, aims to describe how phenomena present themselves in accounts of four fundamental existentials by which all human beings experience the world; through their subjective lived experience of body, human relation, space and time.

Participants
A purposeful sample of seven spouses, 3 women and 4 men, ranging in age from 35 years to 78 years, (median age 58 years), were interviewed. All participants were currently in a relationship with a partner who had been treated at the hospital for cancer in the oral cavity, although they were not necessarily partners to the patients who had participated in study II. All patients had undergone radiation therapy. Surgical treatment was indicated for five of these patients, and had resulted in large intra-oral defects which required reconstruction. These intra-oral defects were not visible, yet had resulted in difficulties in speech, eating, and swallowing for the patients. At the time of the interviews three of the spouses had already witnessed recurrence of their partners’ cancer.

Data Collection
The interviews took place at the hospital dental clinic and were arranged to coincide with appointments the patients, accompanied by their spouses, had at the hospital dental clinic for either post-treatment intra-oral check-ups, treatment of oral complications, or oral rehabilitation. These interviews included five main open-ended questions: 1) How do you feel when you think about your partners’ sickness and treatment? 2) How do you handle your feelings? 3) How would you describe your life today? 4) How do you feel about the future? 5) How did you experience the interview and questions asked? Follow-up and probing questions were used to encourage as detailed and spontaneous descriptions as possible. The interviews ranged in length from 45 to 75 minutes.
Data Analysis
As in the analysis of study II, the four existentials of lived body, relations, space and time were differentiated and used as guidelines for reflection in describing the lived world of those interviewed. Please see page 31 for a detailed description of the analysis of the interviews.

Findings
The findings indicate that oral cancer and its treatment put a tremendous hold on the lifeworld of the patients’ spouses. The essence of their lived experience could be described as ‘living in a state of suspension’, which could be felt throughout the spouses’ experiences of lived relation, lived body, and lived space and time during their partners’ treatment (table 4).

Spouses’ experiences of lived relation
The diagnosis and treatment of oral cancer changed the mutuality and perceptions of roles within the relationship between patient and spouse. The spouse adopted a caring and supportive perspective as the partner slowly became a patient. The spouse, witnessing the signs of the onset of cancer in the life of their partner, most often encouraged their partners to seek help. Many accompanied their partners to meetings with doctors for firsthand information about the diagnosis and future treatment plans.

Treatment start meant physical separation between the spouse and patient, and their time together became limited to visiting hours. As treatment progressed the spouses witnessed their partners’ increasing difficulties and felt all the more compelled to try to give as much emotional support as they could.

Upon coming home, the spouses observed a changed and tired partner with continuing difficulties, and understood their partners’ continuing need for support and encouragement. At this time some realized that their partners’ lives would be drastically changed as a result of treatment, and that some of the changes in mouth functions after treatment would be permanent.

Spouses’ experiences of lived body
The spouses reacted emotionally to their partners’ cancer diagnosis, as they were faced with the prospect of losing their partner. The emotional distress started with concern and worry for their partners as they awaited results of tests and biopsies. Yet hearing the diagnosis of cancer was still shocking for both patient and spouse. For many spouses, a cancer diagnosis still meant possible death.

During the patients’ hospital treatment the spouses, overwhelmed and paralysed by the situation, found it hard to concentrate on their own physical health. An increasing physical fatigue made it difficult to resist negative thoughts, anxiety, and feelings of self pity and they struggled to cope with
these feelings. Some spouses were able to have open and honest discussions with their partners, some found refuge in concentrating on their work, others found help and support in family members or close friends.

The spouses’ physical fatigue continued after the patients’ discharge from the hospital. The end of initial treatment also allowed perspective on the treatment they had been witness to. At this time the spouses’ feelings of relief and joy could be tinged with feelings of guilt about maybe not having given enough support to the patient. The patients’ state of mind and physical health was a continuing source of worry for the spouse. Planning for a future together became difficult, as thoughts and worries about cancer recurrence, living without a partner, were ever present.

**Spouses’ experiences of lived space**

The treatment of oral cancer marked abrupt changes in the lived space of the spouse, as they adapted their life-style to the physical needs and limitations of their partners. Treatment start brought their normal living to a standstill.

During treatment the spouse adjusted to unfamiliar hospital world and routines of treatment. Concentrating on their own normal living habits became difficult as their days could be disrupted by travelling to and from the hospital. Changed living routines at home now meant additional household responsibilities and adjustment to living and eating alone.

The lived space of the spouse remained restricted at treatment end due to the patients’ continuing difficulties with a mouth that had not yet recovered from treatment and did not function normally. This meant, in the first place, frustrating attempts to find food that the patient could enjoy, and accepting in the end that cooking routines and eating habits at home needed to be changed. This, in turn, restricted activities such as eating in restaurants and a return to social life. Travelling together as before became limited, since the patients’ desire to travel had diminished. Yet the desire to continue with previous life-style remained.

**Spouses’ experiences of lived time**

For some of the spouses, time stood still when they were told about their partners’ cancer diagnosis. The events of the day remained etched in their memories. The sense of lived time was altered during treatment, and could be experiences as moving either faster or slower than normal. At treatment end thoughts about the future were positive and focused on living in the present.
Table 4.
Findings – Descriptions of oral cancer patients’ spouses’ experiences of lived relations, body, space and time.

<table>
<thead>
<tr>
<th>PHASE OF TREATMENT</th>
<th>LIVED RELATIONS</th>
<th>LIVED BODY</th>
<th>LIVED SPACE</th>
<th>LIVED TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>Witness to partner’s symptoms before diagnosis. Giving comfort, wanting information from doctors, not wanting to be left out.</td>
<td>Sharing worry about biopsy, initial shock, distress at diagnosis. Why? Expecting worst, death, memories of loved ones lost to cancer.</td>
<td>Normal living brought to standstill. Plans need to be changed.</td>
<td>Time stands still at diagnosis.</td>
</tr>
<tr>
<td>During treatment</td>
<td>Feelings of empathy, sympathy for partner, witnessing difficulties of treatment, giving emotional support.</td>
<td>Not able to function normally, paralysed by situation, trying to cope with partners difficulties, own distress, Increasing physical tiredness, neglect of self.</td>
<td>Unfamiliar hospital world, restricted life space, changed living routines, additional responsibilities at home, not able to work as normally as possible.</td>
<td>May be felt as moving either faster or slower than normal.</td>
</tr>
<tr>
<td>Treatment end</td>
<td>Witness to partner’s difficulties with eating, need for support, sharing partner’s hope for rehabilitation.</td>
<td>Relief, yet worry about future, cancer recurrence, life without partner.</td>
<td>Restricted life space, changed cooking routines, eating habits at home, feeling trapped, changed plans for future.</td>
<td>Hope in a future. Living in present.</td>
</tr>
</tbody>
</table>
Method
The interpretive phenomenology of Martin Heidegger seeks to uncover the meaning of being, and was therefore applied on empirical interview data when searching for the meaning of the oral cancer patients’ experiences of life after treatment.

Participants
In the year 2004, a group of seven patients undergoing treatment for oral cancer participated in study II regarding their experiences of their illness and treatment. Interview questions at that time focused on the patients’ feelings and thoughts during treatment. An attempt to contact all these individuals was made again in the beginning of 2007 for a follow-up interview. Two patients had died during this time period as a result of recurrence. The remaining five agreed to participate again.

Study IV is therefore based on interviews with 2 women and 3 men, ranging in age from 48 to 81 years, (median age 61 years). All had undergone radiation therapy. For 3 patients, where surgical treatment was indicated as well, surgery had resulted in large intra-oral defects which required reconstruction. Rehabilitation of the mouth was still in progress for one of these participants, as the first attempt had not been successful.

Data Collection
The interviews took place at the hospital dental clinic. They were carried out a median time of 4 years after treatment start. All of these individuals still had contact with their doctors at the hospital for yearly post-treatment checkups, as well as contact with the hospital dental clinic for either post-treatment intra-oral check-ups, treatment of oral complications, or oral rehabilitation.

The following questions were used as a guide during the interviews: ‘How would you describe your life today?’ ‘Can you tell me how your life has been since the last time we met?’ ‘Has your life changed after treatment?’ ‘If so, how?’ ‘How do you feel about the future?’ Follow-up and probing questions were used to encourage as detailed narratives as possible. The interviews ranged in length from 60 to 90 minutes.
Data Analysis

A hermeneutic approach, influenced by the philosophies of Hans-Georg Gadamer and Paul Ricoeur, was chosen to analyse and interpret the interview texts. As a final step in the process of interpretation the text was looked upon against the background of the philosophy of Martin Heidegger. By means of Heidegger the interpretations were thus deepened. For more detailed description of the data analysis, please see study IV.

Findings

Analysis revealed that the consequences of oral cancer affected the participants’ experiences of their existence in the world in three ways: how they could exist as themselves, how they felt they existed in the eyes of others, and how they felt they existed in relation to others. These were labelled and described as three themes as follows; ‘existing as oneself’, ‘existing in the eyes of others’ and ‘existing with others’. These themes are presented with their sub-themes in table 5.

Table 5. Findings: New meanings of being-in-the-world, in a both positive and negative sense, made by individuals after treatment of oral cancer.

<table>
<thead>
<tr>
<th>MAKING NEW MEANINGS OF BEING-IN-THE-WORLD</th>
</tr>
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<tbody>
<tr>
<td>Themes</td>
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<tr>
<td>--------</td>
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<tr>
<td>Existing as oneself</td>
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<td>Existing in the eyes of others</td>
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<tr>
<td>Existing with others</td>
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</tbody>
</table>

Existing as oneself

The changed self

A patient with a visible facial disfigurement after treatment could not recognize her thoughts anymore, and appeared to have become a stranger to herself. She realized that the past was unalterable, and felt an overall mood of powerlessness about the present. The future existed so far, as a deep wish, as
something she did not yet dare to believe in. These thoughts and feelings could be understood as existential anguish in a struggle to integrate the present changes in both face and mouth and establish a new self-understanding.

**The self as captive to a changed mouth**

For another patient, life after radiation therapy had resulted in not being able to sleep normally anymore, since he could not escape from his dry mouth, even at night. Even though he stated that he had learned to live with chronic physical tiredness, he admitted that life had generally become more difficult. For this person the world of food had changed as well. His choice of food was limited, and he could not eat when or where he chose. These changed eating habits appeared to have a controlling effect on his life at home and limiting effect on his enjoyment of social activities. The situation presented in the above text brings to light the devastating effects of radiation therapy. His changed lived body now controlled his everyday existence.

**Oneself as normal again**

The consequences of oral cancer do not always require a long period of adjustment. A patient described how, with determination and will power, she had been able to adjust to reconstruction of her mouth with a denture. All she had wanted was to feel like a normal person again. Feeling normal again, for this person, may very naturally be understood as feeling healthy after treatment. It also may have meant not having to think or worry about cancer recurrence.

**Existing in the eyes of others**

**The self as pitied**

In learning to live with a facial disfigurement after treatment of oral cancer came the realisation that people react to disfigurement in various ways. The thoughts of one person before leaving her house now always included wondering how people would react and she admitted that meeting strangers was unexpectedly easier than meeting old friends. Meeting friends from the past could have been a painful reminder of existence lost and new reality, as they revealed how her changed lived body could be seen through the eyes of others.

**The self as confirmed**

In contrast to meeting old friends, where there is an actual meeting and conversation, an individual with a facial disfigurement felt strangers’ reactions by experiencing being stared at, or averted eyes, or being ignored. In being ignored, or stared at, this individual may have felt that her changed lived body was not acceptable in the eyes of others. Her understanding of how she
fitted into the world may have been affected. She described what it meant to be asked about her face by a child, as this simple question helped her feel visible again and confirmed as she is.

**The diminished self**
While a physical defect in the face is visible, a large defect in the mouth, although invisible, may result in difficulties in speech and being understood by others. A patient described how it felt when others pretended to understand what she said when they actually did not. Another patient ended up joking when explaining why he spoke the way he did. Yet this joking may have been a cover for his frustration about not being taken seriously anymore. These individuals were unable to make their meanings understood to others. As a result, they felt the silence of others, which they may have understood as disinterest, or lack of effort on the part of others to try and understand what they said. For these patients this inability to interact with the world as they did before resulted in feeling ‘diminished’.

**Existing with others**

**The abandoned self**
An individual’s understanding of how they fit in the world may be affected when they are ‘left alone’ during sickness. Most patients became aware that peoples’ reactions to just the word cancer varied and that this may be why they felt they were treated differently or socially isolated by friends and acquaintances. A patient reflected on being ‘left alone’ after treatment and said that it takes so little, such as a simple phone call, to help an individual feel that they have not lost their place in the world.

**Oneself as dependent and depending**
The treatment of a life-threatening illness such as oral cancer and living with the consequences can bring about an awareness of deep dependence on others for support and understanding. In feeling how her children not only loved but depended on her, a patient understood how they wanted her to stay alive and expected her to carry on. This individual had realized the effects of her sickness and treatment on her relation to other people. She had realized that, to be part of other people’s being-in-the-world involved both feeling loved, cared for, as well as giving love and caring for.

**Oneself as transformed**
Living with oral cancer may mean living with the constant risk of recurrence. In the following text a patient remembered being told that his tumour had come back. Hearing the news of recurrence brought back memories of the initial treatment and how he had felt then. Comparing himself to the per-
son he used to be, he felt that he had changed so much that he had become a completely different person. In his transformation he realized his previous neglect of his family and the need to change his priorities. Time had become precious, and he had changed his focus to loved ones, to himself, and to living. The meaning of his relations to other people had changed as he had discovered the depth of feelings he felt for family and close friends.
9. Discussion of main findings

Study I revealed that hospital dental staff understood the encounter with head and neck cancer patients in three qualitatively different ways: as an act of caring, as a serious and responsible task, or as an overwhelming emotional situation. The three different ways the encounter was perceived appeared to be related to how the hospital dental staff dealt with feelings aroused during their encounter with the patients.

Understanding the encounter as an act of caring focused on offering holistic care and being patient-centered. Understanding the encounter as a serious and responsible task focused on the treatment and being as professional as possible. While this way of understanding may have allowed dental staff members to feel secure behind their professionalism, the patient may not have felt understood or seen. Understanding the encounter as an overwhelming emotional situation focused on the patients’ cancer, indicating staff members’ possible difficulties in handling strong personal feelings that had been aroused, and resulting in a situation which was undesirable for both patient and staff member. It may be concluded that understanding the encounter as a serious task or as an overwhelming emotional situation could result in difficulties in responding to the patient’s needs. These findings are consistent with previous work on medical professionals’ attitudes and reactions towards patients being treated for cancer 82-85.

The findings of studies II and III have revealed the varying emotional difficulties and support needs of the patients and spouses during treatment. These findings are consistent with previous studies on the needs of cancer patients and their families 17, 86-88. From a psychological perspective, these emotional difficulties can also be looked upon as acute crisis reactions, with periods of shock, reaction, and reorientation to life 89. Patients with oral cancer may experience shock upon receiving their diagnosis. The reaction follows in opening their eyes to the reality of the situation and accepting the treatment plan offered. Towards the end of treatment they begin to look forward to a future, and returning to normal living. Finally, upon coming home, they attempt to reorientate their lives and adjust to a changed way of living.

Another problem posed by cancer from a psychological perspective is that patients cannot be sure for many years whether or not they will survive. This problem involves a continuing unremitting condition of uncertainty for the patients and may affect spouses and family members as well 90. According to Lazarus and Folkman, dealing with uncertainty is a major adaptive task and
can be highly stressful, as anticipatory coping processes can be immobilized \(^90\). The coping strategies for *anticipating* an event may often conflict with the strategies needed to anticipate the events’ *non-occurrence* \(^90\). This was shown by many of the spouses in study III, who enjoyed thoughts of planning for a future with their partner, yet thoughts of planning for the future without their partner were forbidden, and quickly thrown out of their minds. This dilemma may have a disabling effect on both patients’ and spouses’ ability to regain control over their lives again \(^90\).

Study IV revealed individuals struggling physically, emotionally and existentially, to adjust to a changed way of being in the world without seeking help. These findings are similar to the results of a study on the quality of life of head and neck cancer survivors \(^91\). These survivors also seemed to keep their experiences of suffering and cancer-related difficulties to themselves, as they felt they had nowhere to go, and no one who could understand them \(^91\).

**So what is new?**

If the findings of all four studies are consistent with previous work on oral cancer patients, what is new?

Looking upon oral cancer patients and their spouses during treatment with ‘biomedical’ eyes means following the course of a disease in a detached and neutral manner \(^33\). Considering the disease as *separate* from the patient, can mean as well *expecting* and *accepting* the increasing physical symptoms and emotional difficulties as part of the clinical course of the disease and treatment, and not considering the effect they may have on the patient’s life.

Yet the focus of this thesis is oral cancer from a *lifeworld* perspective. And it is just this perspective that revealed, in study I, how the encounter with head and neck cancer patients affected the everyday life, thoughts and feelings of hospital dental personnel. Some were touched by the meeting, some were unprepared for the feelings aroused in the meeting, and some tried to remain neutral.

Studies II and III opened the doors to the patients’ and spouses’ experiences of lived body, lived relation, lived space and lived time during the patients’ treatment. The thoughts and feelings of the patients and spouses during this time showed first, that their needs for support were *greatest* at the end of initial treatment, and secondly, the strong hope for rehabilitation they shared at that time. It also brought to light how upon returning home, left on their own and away from the hospital environment, they realized how their everyday lives were affected by the continuing difficulties with eating, the possible permanent changes in their life-style, and the condition of uncertainty about the future.

Looking upon the patients and spouses from the perspectives of their lifeworlds in this way may allow caregivers to understand the full impact of
oral cancer on the patients’ lives both during treatment, and most important, upon coming home, at treatment end.

In a similar manner, the use of hermeneutics in study IV has shown the continuing impact of oral cancer on the lives of the patients. The changes in the mouth after oral cancer treatment affected the entire being-in-the-world of these individuals. Against the background of the philosophy of Martin Heidegger, these findings reveal how essential the mouth is to a human beings’ identity and existence, something that is not generally reflect upon.

Implications

For members of hospital dental teams

Patients and caregivers share their life-worlds in the setting of the hospital ward. This was true even for hospital dental team members in study I. The encounter with oral cancer patients had a strong emotional impact, and affected them as human beings. As shown in the category `act of caring`, some dental team members, without specific education in caring, had a holistic perspective, and were able to draw on personal resources to offer patients ongoing support, encouragement and compassion.

Holistic caring is of special value to patients with life-threatening diseases such as cancer. What can be done, then, to help the hospital dental team members achieve a holistic perspective? It is important first, for all caregivers to understand that their lifeworlds are always with them in their encounters with patients, and that this affects the relationship they have with them.

Transition to an act of caring as a way of understanding requires self-understanding and self-knowledge. This can be made if the team members are willing to reflect on how their practice and ways of understanding affect the patient. Educational interventions aimed at altering the professionals’ understanding of what should happen in an encounter and how it should be carried out have been described, for example, by Holmström et al. Another form of education for the patient encounter is Balint group participation, which can lead to increased self-understanding, patient centeredness, and increased work satisfaction.

In order for hospital dental personnel to be able to care about patients in a holistic way requires then understanding of their need for self-development from their management. It requires as well support from management when holistic caring involves taking extra time to listen, to talk to, or to encourage worried patients.

From a lifeworld perspective, the difficulties described by the hospital dental teams may be true for other hospital dental team members as well as other disciplines involved on the sidelines in the multiprofessional care and
treatment of patients with oral cancer, such as nutritionists, speech therapists, nursing aides. This suggests that maintaining a high quality in care requires that the organisation of cancer care should consider the identifying the varying needs of all treatment staff. Is this possible if medicine, and dentistry even more so, are still influenced by biomedical models of disease?

**For the spouses**

If the hospital setting is a sharing of lifeworlds between patient and caregiver, as mentioned earlier, it is important to realize that the spouse is a part of the patient’s lifeworld. As such, caregivers should understand the emotional distress of spouses during their partners’ treatment and especially at the time of discharge from the hospital. With this in mind, spouses should also be made aware of expectations regarding future plans from both medical and dental treatment teams. Ongoing dialogue with medical caregivers during treatment about their partners’ prognosis and expected course of recovery may help lessen the spouses’ fears and increase their sense of predictability. And, in rehabilitation of the mouth, it is the dental caregivers that are in a position to help spouses understand treatment options available and probable permanent limitations of oral functions for their partners.

What can be done for the spouses once their partner has come home from the hospital and they are faced with living in a condition of uncertainty about their partners’ future? From a holistic perspective, we should try to help them. Yet this raises many moral and ethical questions. What does the healthcare system want to do? What can be done? What should be done?

**For the patients**

The findings of studies II and IV revealed the patients’ increasing need for emotional support during treatment and continuing need at treatment end. How can these patients be helped? It is well known that the treatment of any cancer is affected by the fact that cancer is life-threatening. As a result, all the more attention is being paid by treatment staff members to patient-centered and holistic care of cancer patients during treatment. Psychologists, oncologists or oncology nurses strive to help patients with issues such as adaptation and coping, anxiety, distress, social support, social rights and occupational issues at psychosocial oncology clinics in many cancer centers and university hospitals. Nursing staff with direct daily contact with the patients on the wards as well, are aware that these issues may be important to cancer patients, and strive to listen and give comfort during treatment.

The patients’ need for ongoing and increasing help with physical care of the mouth during and after radiation treatment is in accordance with previous studies on patients with oral cancer or other cancers in the head and neck.
region, which have described patients’ all-increasing problems with eating and pain during radiation therapy. All increasing problems with pain have been noted as well in patients receiving radiotherapy for cancers in the breast, bladder, prostate, rectal cancer, among others. These patients’ needs for ongoing monitoring and support were met at nurse-led support clinics.

Larsson (2005), in her study on the eating problems of patients with head and neck cancer advocated a supportive nursing care clinic as a complement to regular care to support the patients with their eating problems during and after radiation therapy and improve the quality of care. I agree that the patients in studies II, and, for that matter, many patients undergoing treatment for cancers in the head and neck region would benefit from care at a support clinic, organized as a complement to regular treatment.

From the perspective of the patient’s lifeworld, how should this support clinic be organized? The treatment and management of patients with oral cancer may involve as many as twenty different disciplines. The needs of the patients may be multiple, and thus involve members of these different disciplines. How can the patients be helped when communication between multiprofessional treatment teams has been shown not to be effective and has resulted in poor continuity of care? The period following discharge, when the patients had the greatest need for information and support, such as what to do to minimize ongoing side effects, or where to go for help if necessary, is most often a communication ‘pitfall’. Collaboration between medical and dental teams may be limited as well. Studies reveal that oral problems during cancer treatment are often underdiagnosed by doctors, and not addressed by nursing staff. Barriers to interprofessional collaboration in the treatment of oral cancer may even exist within both the medical and dental professional disciplines.

One suggestion, from a holistic perspective, is to have a central support clinic take over responsibility of organizing multiprofessional support. This setting would allow the patients’ unique needs to be met by the right caregiver. At the same time, it would facilitate a sharing of lifeworlds between multiprofessional caregivers, improving communication and collaboration and resulting in a closer organisation, and better understanding between participating specialities. Is this possible?

And still, what can be done to help the patients in study IV, once they are home, struggling to live with the consequences of their treatment. As with the spouses, there are many moral and ethical questions that need to be answered first. The first and most important question is how patients themselves may wish their needs to be met. Should the organisation of oral cancer care keep its doors open to include helping those patients who may be in need of emotional and existential support after they have left the hospital? If so, how long?
Are there other ways the patients can be helped? Support groups, arranged during rehabilitation, or as part of outpatient programs, can give patients the chance to gain emotional support from each other, and can also help to relieve the distress of their spouses and other family members. Web sites on the Internet, as well, allow those individuals involved with oral cancer, such as patients, survivors, spouses, family members and caregivers, to share experiences and find inspiration in each other. On-line care might be more developed in the future.

Discussion of methods

The question of trustworthiness
An important issue in the methods chosen for this thesis was to follow quality criteria for qualitative studies as identified by Guba and Lincoln (1989): credibility, dependability, confirmability and transferability. In striving for credibility, the procedures of data collection and analysis were presented as thoroughly as possible, to show that the findings were grounded in data material. To uphold the criterion of dependability, the research process was described in detail in an attempt to make it easy for the reader to understand how I came to my conclusions. Confirmability was assured in the findings of the four studies this thesis is based upon by the use of citations to show that the results were firmly grounded in the interview texts. Furthermore, analysis of all four studies was conducted with my supervisors as co-readers. Possible emerging categories in study I, essences in studies II and III, and possible explanations, understandings and interpretation in study IV were discussed together until agreement was reached.

Transferability refers to the notion that the results can be useful in other settings or groups. This may be true when reflecting on the results of study I. The situation and difficulties described by this group of hospital dental team members may be true for other hospital dental team members as well as other disciplines involved in the multiprofessional care and treatment of patients with oral cancer. The results of studies II and III are based on a small sample of 7 participants. The sample size decreased to 5 in study IV due to the death of two participants. This situation is not uncommon when studying oral cancer, as patient withdrawal rate may be high due to intensity of treatment, recurrence of patients’ cancer, or death of patient. The findings of studies II, III and IV, however, might be transferred to other patients treated for cancers in the breast, bladder, prostate, rectal cancer, among others. These studies have also confirmed how unique the experience and understanding of oral cancer can be for each individual involved.
The question of preunderstanding

Another important issue to discuss is the question of preunderstanding. As a hospital dentist, doing research on colleagues, patients and spouses that I met in the course of my work, I was aware of the risk of my own preunderstanding in my research. Where to look? The philosophies of phenomenology and hermeneutics had some answers.

Husserl believed that the practice of epoché (bracketing out our familiar way of thinking about a phenomena) and then shifting from the natural attitude to a `phenomenological´ attitude was the way to be open-minded and suspend preconceptions (or preunderstandings as they may also be called) \(^{64}\). I accepted this method initially as a way of attaining objectivity in my studies.

But reflection on the thoughts of Heidegger made me realize that it was not so easy to bracket out a way of thinking about something. According to Heidegger, it is not possible to put aside our preunderstandings or familiar way of thinking about the world since we are always a part of the world we live in \(^{75}\). I realized then that pure objectivity was not possible.

Gadamer, in his book Truth and Method, introduced new perspectives on preunderstanding and pointed me in the direction of language and text for the first time \(^{78}\). While Husserl focused on the need for bracketing preconceptions or preunderstandings, Gadamer explained what the term meant and what it was based upon. He believed that our understanding of a situation is always grounded in our preunderstanding of it, since we are always influenced by our history and tradition \(^{78}\). Gadamer also believed that this preunderstanding could either obstruct a correct understanding or could lead to a better understanding of a situation \(^{78}\). In this way my experience as a hospital dentist was an advantage, as it allowed me to gain access to the individuals involved in my studies and I could better understand their descriptions of treatment.

For Ricoeur it was the text, and not the author that was interesting. Interviews that are taped and transcribed can be seen as `fixated speech´ \(^{79}\). The person interviewed becomes the author while the interviewer is the co-author, who can dominate the situation without being aware of it \(^{110}\). During my interviews I had spoken directly to the informants, and was able to ask questions if anything was unclear. Here there was a risk that my preunderstanding could affect the follow-up questions in such a way as to get the answers I expected.

Ricoeur meant as well that a text can have many meanings that the author may not be aware of.\(^{79}\). With this in mind, it is very possible that other researchers would have revealed different meanings and dimensions in the experiences of the informants. My findings represent hence one of many possible interpretations.
In summary, the above reveals the issues I have had to deal with in my research – striving to be as neutral as possible, becoming first aware of, then distancing my self from my preunderstanding, and in some respect gaining control over my subjectivity. My supervisors and members of the multi-professional Health Services Research group have helped along the way. They have constantly reminded about the risks of my dental pre-understanding. At the same time, they have enriched me with their thoughts and reflections, and I have had an opportunity to reach a new understanding.
10. Conclusions

- Hospital dental personnel in study I understood their encounter with head and neck cancer patients in three different ways – some focused on the patient, some on the treatment, some on life-threatening aspects of cancer. The encounter had a strong emotional impact, and affected them as human beings. The three different ways the encounter was understood appeared to be related to how the dental hospital staff dealt with feelings aroused during the encounter. These findings indicate that they are not always able to lean on education and professional training in finding ways of dealing with situations with strong emotional impact.

- The lifeworld of the oral cancer patients in study II changed drastically during treatment. The central theme that emerged was the patient’s increasing embodiment in a mouth that slowly became ‘uncanny’, or unreal as it slowly ceased to function normally. The findings revealed the patients’ increasing need for support during treatment and continuing need at treatment end after discharge from the hospital.

- Oral cancer and its treatment put a tremendous hold on the lifeworld of the spouses in study III, which was experienced as ‘living in a state of suspension’. The findings revealed the emotional distress of spouses during their partners’ treatment and especially at treatment end, when, with their partner home from the hospital, they realized how their everyday lives were affected by the consequences of their partners’ sickness.

- To live with the consequences of oral cancer meant, for the five individuals in study IV, struggling, physically, emotionally and existentially, to adjust to a new way of being in the world without seeking help. These findings have shown the continuing impact of oral cancer on the everyday lives of the patients.

- This thesis presents how taking into consideration the lifeworld perspective of human beings may have consequences for the healthcare system, and raises the question if a perspective of wholeness in the organisation of oral cancer care could meet the varying needs among treatment staff, the patients, and their spouses.
Reflections

In the preface I had wondered about my colleagues, and how they experienced their meeting with oral cancer patients. With the help of phenomenography I realized that not all had felt as I did, that there were variations in the way people understood situations. This was, for me, a very positive revelation, as I suddenly better understood why people around me at work had acted and reacted so differently.

I had wondered about the patients - how they were affected by their sickness and treatment – and their spouses. I wondered if we, as members of hospital dental teams, really could understand how they experienced their situations, and what was important to them. The use of phenomenology and the four existentials opened some of the doors to the thoughts and feelings of the patients and spouses, revealing the significant impact of oral cancer in their lifeworlds. The use of hermeneutics revealed the world that opened up in some of the interview texts, showing me what it can mean for individuals to live with the consequences of oral cancer. In this manner I believe I have an idea as to the thoughts and feelings of the patient in the dental chair, or the spouse by the patient’s side.

Are we really helping the patients? In my role as a hospital dentist I was aware of our ability to prevent infection and ease the severity of oral complications during radiation treatment of oral cancer. I was also able to observe the work of specialists in surgery and prosthetics in reconstruction of the mouth, and could understand how complex and difficult reconstruction could be after oral cancer surgery. The findings in this thesis have shown the importance of reconstruction to the patients in this study, how their most important desire after initial treatment was to have a mouth that functions again. So here to, the answer, I believe, is yes, our work is highly valued by the patients.

Can we do more? Working on this thesis has made me believe that dentistry is in a position to do much more if it realizes that there is a sharing of lifeworlds between patients and dental personnel in the dental environment as well. A holistic view of the patients would mean taking full responsibility for not just teeth, but also the mouth, and even the needs of the whole patients. This would help dentists realize their responsibility in the prevention and early detection of oral cancer, prevention of tobacco use, as well as and offering patients counselling in cessation of tobacco-use and alcohol. Dentists themselves are divided in this aspect, as shown in two interesting debate articles in the Journal of American Dental Association. One author stated that in changing the title ‘dentist’ to ‘oral physician’, dentists
would be recognized as providers of services such as oral cancer screenings, tobacco-use cessation as well as traditional dental procedures. This was commented on by another dentist who believed that dentistry must remain dentistry, and dentists should focus on restorative dentistry and rehabilitation of the masticatory system.

A study by Horowitz et al (2000) on dentists’ opinions and practices regarding oral cancer prevention and early detection revealed that only 14 percent of the dentists routinely provided oral cancer examinations, 25 percent agreed that they had been adequately trained to provide oral cancer examination, and 28 percent believed that they were adequately trained to provide tobacco cessation counselling. The above mentioned study suggests that dental school curricula should place greater emphasis on oral cancer prevention and early detection.

Should not dental school curricula even teach a holistic perspective on patients and dental personnel? Would this not be of help in the treatment of patients with special needs?

And now, the final question. Can I say, at the end of this thesis, that I understand oral cancer? This is difficult to answer. Is it possible to understand any illness? I hope, however, that I have shed some light on important aspects of oral cancer, which have increased the readers’ understanding of it.

Yet I do understand that oral cancer is a disease where treatment itself can be complex, difficult, and can leave a patient with oral dysfunction and facial disfigurement. The overall survival rate is poor, yet I do not know the future for the patient in front of me. The strongest impression was that all the patients and spouses in this study experienced a hope of survival at the end of initial treatment. Oral cancer is a disease where dentistry must strive to give both patient-centered and holistic care, and see the teeth, the mouth, and the patient as a unique individual.

"The patient hasn’t given up hope
and we haven’t given up hope
and no one has
we just keep on trying to help as fellow human beings
and treat them with as much dignity as possible
all the time"
11. Future research

The findings of the four studies have shown the importance of effective collaboration and communication between multiprofessional treatment teams for optimal treatment of oral cancer patients. Yet the varying difficulties and needs experienced by the oral cancer patients, their spouses and members of the hospital dental treatment teams in these studies suggest that improvements in the present multiprofessional team approach may be needed. Therefore, it may be of value to investigate if barriers in multiprofessional collaboration and communication exist, if so, what they are, and if they may be overcome.

As there is little knowledge of the opinions of other individuals involved in the treatment of head and neck cancer, an interview study with key persons involved in the present multiprofessional treatment of oral cancer, such as dieticians, therapists, ear, nose & throat specialists, plastic surgeons, oncologists, may aid in gaining insight into their lifeworlds. Knowledge gained from this study may then constitute a basis for improving the multiprofessional organisation of oral cancer care and guiding the development of multiprofessional support clinics for head and neck cancer patients.

Thereafter, it would be interesting to study how the medical treatment staff members experience their encounter with the oral cancer patients. Using the same phenomenographic method approach as in studying hospital dental team members would complete the picture of all professionals involved in the treatment of oral cancer patients and reveal possible similarities or differences in support and education needs.

Study I revealed the need for research in competence development in the dental treatment team. Further exploration and identification of the difficulties and needs of competence development for each separate discipline within the dental team may reveal if, and to what extent, the ways of understanding the encounter are affected by education and professional role. And, as mentioned in study I, an interesting field for further studies would also be to investigate the impact of the dental staffs’ different ways of understanding the encounter on a patient level.

Continuing along the same line, further research in identifying the cancer education needs of all professionals and non-professionals involved in treatment of head and neck cancer may aid in the development of multiprofessional postgraduate education in oral cancer care.
Qualitative studies using a phenomenographic method approach would be of value in studying how dental personnel understand their encounter with other groups of patients, for example, dental phobics. Generally speaking, more qualitative research in dentistry is needed to study the ‘human’ aspect of the profession.
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Oral cancer är inte enbart livshotande utan kan ge svåra defekter i ansiktsregionen och påverka centrala funktioner som smak, tal, tugg- och sväljförmåga. Tandvårdpersonalens roll i behandlingen av patienter med oral cancer under deras sjukhusvistelse och rehabilitering kan bli både långvarig och intensiv. Medan utbildning i cancervård är tillgänglig för den medicinska vårdpersonalen är tandvårdspersonalen hänvisad till sig självt utan någon specialutbildning eller handledning.

Hur kan medlemmar i tandvårdsteamet få en bättre förståelse för patienterna och den egna rollen i behandlingen? Patienterna och deras partners – hur påverkas de av sjukdomen och behandlingen? För att få svar på dessa frågor har fenomenologins, hermeneutikens och fenomenografins teorier och metoder utnyttjats i fyra delstudier för att vetenskapligt identifiera, beskriva och tolka empiriska data vilka samlats in genom djupintervjuer med sjukhus- tandvårdspersonalen, patienter och deras partners.

**Studie I** visar att sjukhustandvårdspersonalen uppfattar mötet med patienterna på tre kvalitativt olika sätt - som ett starkt omvårdnads engagemang, som en allvarlig och ansvarsfull uppgift och som en känslomässigt överväldigande situation. Resultaten pekar på att sjukhustandvårdspersonalen inte kan förlita sig på sin yrkesutbildning för att hantera svåra känslomässiga situationer. **Studie II** ger en insikt i oralcancerpatienternas livsvärld under själva behandlingen. Essensen av deras upplevelser kan beskrivas som att vara fångad i en mun som känns allt mer ´overklig´ medan den långsamt upphör att fungera. Kärnan i partnerns upplevelser av oral cancer i **Studie III** kan beskrivas som att ´hänga i luften´ eller att leva i ett anspänningstillstånd. Resultaten pekar på att både patienterna och deras partners behov av stöd kan vara störst i slutet av behandlingen när de återvänder hem och konfronteras med den ackumulerade och uppdämda reaktionen på alla upplevelserna kring sjukdom och behandling. **Studie IV** ger en insikt i vad det kan betyda för människor att leva med konsekvenserna av oral cancer och visar på en tyst fysisk, känslomässigt och existentiell kamp för att anpassa sig till ett nytt liv.

Avhandlingen belyser livsvärldsaspekter hos patienter med oral cancer, deras partners och sjukhustandvårdspersonalen och ifrågasätter om organisationen av dagens cancervård kan hantera människors emotionella och existentiella svårigheter och behov.
14. References

38. Rothwell PM. External validity of randomised controlled trials: "to whom do the results of this trial apply?" Lancet 2005;365(9453):82-93.
A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine”.)