Oral Health and Experience of Oral Care among Cancer Patients during Radio- or Chemotherapy

BY

KERSTIN ÖHRN
Dissertation for the Degree of Doctor of Philosophy (Faculty of Medicine) in Caring Sciences presented at Uppsala University in 2001

ABSTRACT


Oral complications and symptoms are common among patients with cancer. The aim of this thesis is to study several aspects of oral status, oral health and its relation to quality of life, and oral care among patients treated with radiotherapy or chemotherapy. Descriptive, comparative and correlational designs were used.

A series of consecutive patients admitted to a university hospital or a regional hospital to receive radiotherapy for head and neck cancer or chemotherapy for haematological malignancies, were studied prospectively with regard to oral symptoms and their relation to health-related quality of life using interviews and questionnaires, examination of the oral cavity and saliva tests. All nurses and enrolled nurses who worked with these patients or with patients with lung cancer were interviewed about their education and knowledge in oral care and performed oral care. The medical and nursing records on patients with these cancer diseases at the two hospitals were reviewed.

The results indicate that patients receiving radiotherapy experienced increasing oral symptoms, which remained to a large extent one month after treatment. Patients receiving chemotherapy did not experience oral symptoms to the same extent. The oral symptoms were significantly related to patients’ health-related quality of life, particularly among those receiving radiotherapy. Data also indicate that there is a lack of adequate education and continuing education in oral care among nursing staff. All patients were not examined orally before or during treatment, nor did they receive sufficient information or instruction related to oral hygiene. Patient compliance with oral hygiene procedures was acceptable, although some patients reported difficulties. Oral status and oral care were insufficiently documented, particularly in nursing records. The attitudes to oral examination and discussion on oral hygiene differed between nursing staff and patients. Nursing staff objected to examining the oral cavity referring to patient integrity. This was not considered as a hindrance among patients. In conclusion, oral health is related to health-related quality of life, which motivates a multi-disciplinary approach to oral care.

Key words: Oral health, oral status, health-related quality of life, oral care.

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ISSN 0282-7476
ISBN 91-554-4949-9

Printed in Sweden by Uppsala University, Tryck & Medier, Uppsala 2001
To
Staffan and Leonard
This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


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PAPERS I - V
INTRODUCTION

The oral cavity is of central importance to most people. Verbal as well as non-verbal communication is performed through the oral cavity. Nutritional intake, essential for survival, depends on a well-functioning oral cavity. The anatomy of the oral cavity also contributes to a person’s appearance.

Within health care, there is a long tradition of separating the oral cavity from the rest of the body. In Sweden there are separate organisations and laws directing health care and dental care. The insurance systems are different, and in addition, the educational system is divided in terms of medicine/nursing and dentistry/dental hygiene. This is unfortunate, since many common diseases and medical treatments involve the oral cavity and give rise to oral symptoms, and some oral diseases compromise general health (Mendieta and Reeve, 1993, Scully and Cawson, 1987). Multidisciplinary approaches and an extended teamwork are of vital importance to provide the best care possible including the oral cavity.

It is of interest to investigate how patients with diseases and/or treatments that comprise the oral cavity experience oral care and to investigate patient experiences of oral symptoms in relation to their quality of life. This thesis concerns oral health and experiences of care among patients with cancer, treated with radio- or chemotherapy.

The diseases and their treatment

Head and neck cancer

The term head and neck cancer comprises mainly squamous cell carcinoma and adenocarcinoma. It includes cancer of the lips, oral cavity, pharynx, larynx, nasal and paranasal sinuses, neck, ear and salivary glands. Approximately 1,000 new cases are diagnosed yearly in Sweden, and the prevalence increases with age. Nearly one third of the cases are women and two thirds are men (Cancer Incidence in Sweden, 2000). The five-year survival rates vary between 50% and 90%, and have remained almost unchanged for decades. Survival rates vary mainly with the site of the tumour, the pathological classification and the stage of the disease (Cancer i Siffror, 1998). The tumours are usually treated with surgery and/or radiotherapy and in some cases also chemotherapy.

Haematological malignancies

Haematological malignancies include several types of diseases such as lymphoma, leukemia and myeloma. The leukemias are a heterogeneous group of neoplasms arising from malignant transformation of hematopoietic cells. Approximately 3,200 new cases were diagnosed in Sweden in 1998, with an increasing trend for lymphomas. More men than women are affected (Cancer
Incidence in Sweden, 2000). The five-year survival rate varies between 10% and 50% and has improved over the last two decades especially for lymphoma (Cancer i Siffror, 1998). The treatment includes chemotherapy, radiotherapy and bone marrow transplantation.

**Small cell lung cancer**
Lung cancer is classified into non-small-cell lung cancer and small-cell lung cancer. Approximately 3,000 new cases were diagnosed in Sweden in 1998. Approximately one-third of the cases are women and two-thirds men with an increasing trend among women (Cancer Incidence in Sweden, 2000). The five-year survival rate is approximately 10% (Cancer i Siffror, 1998). The treatment for small-cell lung cancer consists mainly of chemotherapy.

**Radiotherapy**
Radiotherapy of malignancies of the head and neck region often includes the major and minor salivary glands depending on the location of the tumour. The total dose of radiotherapy varies between 50 and 75 Gy delivered with fractionated irradiation in doses of 2 Gy per day or 1.2 Gy twice daily during 5 days/week. Treatments are usually delivered on an outpatient basis.

**Chemotherapy**
Chemotherapy is usually given in cycles every third to fourth week with varying intensity depending on the disease. It has become more and more common to treat patients on an outpatient basis. This is true particularly for patients with lymphoma, myeloma and lung cancer. Patients who receive more intensive chemotherapy may spend some time in hospital due to their medical condition. When patients have leukopenia, they are usually isolated in hospital.

**Oral effects of radio- and chemotherapy**
Both radiotherapy and chemotherapy constitute a challenge to the patient’s oral status. Almost 100% of patients receiving radiotherapy for head and neck cancer develop some oral complication while the corresponding figure for patients receiving chemotherapy is approximately 40% (Lunn, 1998, Sonis et al., 1999, Spijkervet et al., 1989). The patient’s defence mechanisms may be impaired by cancer treatment or by the disease itself. Both therapies impair cell division and disrupt normal replacement of oral mucosa resulting in mucositis (Jansma, 1991, Schubert et al., 1999, Sonis, 1998). In addition, radiotherapy involving the salivary glands causes xerostomia, which may lead to taste loss and an elevated level of cariogenic bacteria. This may result in dental caries and make patients more liable to infections. Oral musculature and alveolar bone are other tissues that may be damaged by radiotherapy causing trismus and osteoradionecrosis (Heimdahl, 1999, Jansma, 1991). Chemotherapy may cause myelosuppression, immunosuppression, mucosal
lesions, haemorrhage and taste alterations. The disruption of the oral mucosa in a myelosuppressed patient may lead to systemic infection (Heimdahl, 1999, Peterson, 1992, Schubert et al., 1999). The present study involves a comparison of the frequency of oral symptoms, complications and oral care between patients receiving radiotherapy and those receiving chemotherapy.

**Oral health, oral symptoms and oral complications**

Oral health includes patients’ experiences of and attitudes to oral status. In the present study, the term oral symptoms refers to patient experiences, whereas “oral complications” is used to denote phenomena assessed by staff. Different populations, diagnoses, medical treatments, assessment methods and assessment times have been suggested to explain the variation in reports of oral symptoms and complications (Dodd et al., 1996)

Symptoms and complications related to saliva

Saliva has a great number of digestive and protective functions and is important for the ability to talk. Saliva lubricates the oral cavity and provides buffers, minerals and proteins that serve as a protection from infections (Ekström, 2000, Tenovuo and Lagerlöf, 1994). When the salivary glands are located within the field of radiation, salivary production may be totally or partly reduced (Franzén et al., 1992, Leslie and Dische, 1994)

Studies have demonstrated that 81% to 100% of patients receiving radiotherapy directed towards the oral cavity including the salivary glands, experienced mouth dryness (Bjordal et al., 1995, Bundgaard et al., 1993, Franzén et al., 1992, Karlsson, 1987, Kuten et al., 1986, Langius et al., 1993, Niedermeier et al., 1998). Many patients find mouth dryness to be a significant cause of distress (Holmes, 1998), which may affect eating and increase the risk of inadequate nutrition (Backstrom et al., 1995). Speech difficulties were reported by 51% six months after radiotherapy according to Epstein et al (Epstein and Chow, 1999). Xerostomia has also been reported among 79% of patients receiving bone marrow transplants after total body irradiation (Bågesund et al., 2000, Chaushu et al., 1995), and 44% of patients with advanced cancer mentioned dry mouth as a symptom to their physician (Oneschuk et al., 2000)

Studies among patients receiving radiotherapy report that saliva may change and become more viscous and sticky (Bernhoft and Skaug, 1985, King et al., 1985, Kuten et al., 1986). Viscosity increases with a reduction of the secretion rate (Bernhoft and Skaug, 1985)

In several studies, reductions have been reported in stimulated (Eisbruch et al., 1999, Epstein et al., 1998, Franzén et al., 1992, Niedermeier et al., 1998) as well as unstimulated (Eisbruch et al., 1999, Epstein et al., 1998, Kuten et al., 1986) salivary secretion rates among patients receiving radiotherapy. The salivary secretion rate seems to decrease rapidly after approximately one week at a dose of 10 Gy (Epstein et al., 1998, Franzén et al., 1992, Niedermeier et al., 1998).
For patients receiving chemotherapy, the literature reports divergent results. Wahlin (Wahlin, 1991) demonstrated a temporary reduction of the stimulated secretion rate among patients with leukemia 1 - 3 days after the start of chemotherapy. No change in stimulated secretion rate was reported among patients with lymphoma (Laine et al., 1992, Meurman et al., 1997).

There is a lack of knowledge about the extent to which patients receiving chemotherapy for haematological malignancies experience mouth dryness. Lip dryness can be a significant problem for patients receiving chemotherapy but no incidence figures have been reported.

Symptoms and complications related to the oral mucosa

The oral mucosa consists of epithelium and connective tissue and is the first line of defence (Heimdahl, 1999, Sonis, 1998). Proliferating malignant cells are most susceptible to the effects of irradiation and chemotherapy. However, normal cells are also susceptible to those effects, which are most pronounced in tissues with a rapid turn-over of cells, for example oral and gastro-intestinal epithelia and bone marrow. Chemotherapy may thus cause mucositis both through a direct effect on the epithelia and through bone marrow effects causing leukopenia. This may result in a propensity for infections in a complex interaction with the oral microflora (Sonis, 1998). The oral cavity contains micro-organisms that are normally harmless, but which under certain circumstances may cause infections of viral, fungal or bacterial origin (Heimdahl, 1999, Schubert et al., 1999).

Pain is a pronounced symptom of mucositis and candidiasis. Among patients receiving radiotherapy, pain was reported by 58% six months after treatment (Epstein et al., 1999). In addition, oral pain has been reported in studies of quality of life but no frequency figures were presented (Bjordal et al., 1995, Hammerlid et al., 1997a). Several studies demonstrate that pain is a frequent side effect with an incidence of 67% to 86% among patients receiving chemotherapy (McGuire et al., 1993, McGuire et al., 1998, Persson et al., 1995). Pain may complicate swallowing, resulting in an inadequate nutritional intake.

There is a large number of methods to assess mucositis. The variability of methods used for mucositis assessment is a barrier to comparisons of incidence as well as studies of interventions for prevention or treatment of mucositis (Parulekar et al., 1998, Schubert et al., 1992). Newly developed instruments have been presented in recently (McGuire et al., 1999, Schubert et al., 1992, Sonis et al., 1999). Hopefully, these will facilitate future research.

Candida infection is the most common oral fungal infection in myelosuppressed patients during and after radiotherapy (Heimdahl, 1999, Jansma, 1991, Lunn, 1998, Schubert et al., 1999). Reports show that 57% to 89% of patients with cancer have positive cultures for candida species (Wilkes, 1998). A dry mouth predisposes patients to develop oral candidiasis (Lunn, 1998). In addition, patients may be affected by viruses and bacteria causing systemic infections (Heimdahl, 1999, Schubert et al., 1999). The incidence of herpes simplex virus infections varied from 65% to 90% in seropositive patients receiving intensive chemotherapy and bone marrow transplants (Wilkes, 1998). Oral hemorrhage may occur during treatment-induced thrombocytopenia with a frequency of 15% (Dreizen, 1990).

Symptoms and complications related to nutrition
An adequate nutritional intake is important for patients treated with chemo- or radiotherapy. However, cancer is often accompanied by weight loss (Hammerlid et al., 1998, Posner et al., 1985, Skolin et al., 1997). Taste alterations and loss of appetite are common side effects of both chemo- and radiotherapy (Bernhoft and Skaug, 1985, Bundgaard et al., 1993, King et al., 1985, Kuten et al., 1986, Langius et al., 1993, Lockhart and Clark, 1990, Persson et al., 1995, Skolin et al., 1997), which may be one reason for weight loss and a poor nutritional intake. Dysphagia, another common side effect, (Andersson et al., 1999, Bundgaard et al., 1993, King et al., 1985, Kuten et al., 1986, Lockhart and Clark, 1990) and trismus (Jansma, 1991) may also interfere with an adequate nutritional intake. Many patients complain about eating difficulties when assessed for quality of life but no exact frequency figures have been presented (Bjordal et al., 1995, Langius et al., 1993, Persson et al., 1995).

In summary, among patients receiving radiotherapy, major symptoms and complications related to saliva have been described in the literature. However, there is a lack of knowledge on mouth dryness, lip dryness and salivary viscosity among patients receiving chemotherapy. Mucositis has been extensively investigated in the dental literature but is seldom connected to the experience of pain among patients receiving radiotherapy. There is a scarcity of prospective studies with repeated assessment of symptoms experienced by patients and their relation to complications assessed by professional staff.
Health-related quality of life (HRQOL)

Quality of life is a concept used in many disciplines to incorporate a variety of aspects of an individual’s life. HRQOL is a multidimensional concept dealing with quality of life related specifically to health and disease. There is no single unequivocal definition of HRQOL (Gotay and Moore, 1992), but there is an increasing consensus that HRQOL refers to the physical, psychosocial and social functioning of patients and the impact of disease and treatment on their abilities and daily functioning (Forsberg, 1996). Assessment of quality of life may help to identify patients with severe physical and/or psychosocial problems (Bush et al., 1995, Hammerlid et al., 1999, Osoba et al., 1998, Zittoun et al., 1999).

Dental research and clinical practice have traditionally concentrated mostly on dental and medical diagnoses assessed by professionals, largely disregarding patient experiences. Today, research on quality of life in an oral/dental perspective is growing and there is an interest in introducing the concept oral health-related quality of life. This has been studied mostly among the elderly (Locker and Slade, 1994, MacEntee et al., 1997, Slade et al., 1996). It has been operationalised by a variety of variables assessed by dental professionals such as dental caries, periodontal disease or oral soft tissue conditions. This indicates that oral health is often conceptualised in terms of the absence of disease.

According to Gift et al (Gift et al., 1997), it is difficult to find unique factors identifying oral health, which implies that oral health is a part of general health. Gift and Atchinson (Gift and Atchison, 1995) emphasise three approaches to oral health-related quality of life: The oral cavity in itself; the impact of the oral cavity on the rest of the body and vice versa. These approaches indicate the oral cavity as an integral part of the body, which may have an impact on general health. Also, general health may have an impact on the oral cavity. In an interview study on the significance of the mouth in old age, MacEntee et al (MacEntee et al., 1997) found that oral health was an interconnected mix of three dominant themes: comfort (including pain and eating), oral hygiene (the significance of a clean mouth from a personal and a social perspective) and general health (“your mouth and your body flow together”). Patients considered oral health to be a part of general health. Both Gift et al and MacEntee et al demonstrate relationships between the oral cavity and the rest of the body, which necessitate considerations of the oral cavity when diagnosing and treating patients. This is particularly important for patients with serious diseases demanding comprehensive medical treatment that has an influence on the oral cavity.

Several studies have been performed on HRQOL among patients receiving radiotherapy for head and neck cancer (Allison et al., 1999, Bjordal et al., 1995, Bjordal et al., 1994b, Bjordal et al., 1999, Epstein et al., 1999, Gotay and Moore, 1992, Hammerlid et al., 1997b, Hammerlid et al., 1997a, Langius, 1995, Rathmell et al., 1991, Sherman et al., 2000). The findings show that oral symptoms have an influence on patients’ everyday life and that such symptoms may influence
quality of life negatively. In studies of HRQOL among patients with haematological malignancies, oral symptoms have been reported to be very distressing (Bush et al., 1995, Persson et al., 1995, Zittoun et al., 1999).

In conclusion, there is a growing interest in HRQOL in dentistry. Studies have been performed using specific instruments for head and neck cancer patients. However, there is a lack of knowledge about the influence of oral symptoms on HRQOL, particularly among patients receiving chemotherapy. There is no previous study in which patients have been interviewed regarding their experiences of oral symptoms and their relation to HRQOL.

**Nursing staff education, knowledge and attitudes to oral care**

Oral health care is a daily routine of hygiene for most people. Patients suffering from a disease, undergoing treatment that affects the oral cavity may need specific oral hygiene routines or even assistance from dental or health care staff or relatives. Research on knowledge and attitudes related to oral issues among nurses has often been performed among staff in care of the elderly (Boyle, 1992, Nordenram, 1997, Paulsson et al., 1998, Wårdh et al., 2000). Nieweg et al (Nieweg et al., 1992) and Sweeney et al (Sweeney et al., 1998) found that the education of the nursing staff in charge of patients with cancer was insufficient. In a recent study by Paulsson et al (Paulsson et al., 1998), it was found that the knowledge among nursing staff in care of the elderly increased after a continuing education session. Even though the majority of nursing staff consider oral care to be an important part of good nursing, it is still a neglected part and oral hygiene seems to be difficult to provide (Boyle, 1992, Nordenram, 1997, Wårdh et al., 2000). However, attitudes and subjective norms predicted 39% of the behaviour to provide oral care among nurses (Wallace et al., 1997). In a study by Larson et al (Larson et al., 1993), nurses and patients agreed that mucositis was one of the most distressing symptoms, but stomatitis was rated very low in a study on research priorities among oncology nurses (Whelan-Funkhouser and Moeller-Grant, 1989). Löfmark et al (Löfmark et al., 1999) found that both nurses and nursing students underestimated patient experiences of a dry mouth.

Little is known about education, knowledge and attitudes to oral care among nursing staff caring for patients with cancer and if their attitudes are in accordance with patient attitudes.
Oral care
Oral care should be both preventive and therapeutic to minimise the risk for oral complications and symptoms and to prevent systemic complications. A multidisciplinary approach has been advocated to provide proper oral care for these patients (Jontell and Koch, 1995).

Dental care
Today, there is consensus that patients receiving chemo- or radiotherapy should be examined by dental staff and necessary dental/oral treatment should be administered before the start of the medical treatment. In addition, appropriate prophylaxes should be introduced (Jansma, 1991, Jontell and Koch, 1995, Heimdahl, 1999, Lunn, 1998, National Institute of Health Consensus Development Conference, 1989). However, not all patients develop oral complications or experience oral symptoms, why it is a delicate task to predict who is at risk. Intensive chemotherapy and high doses of radiotherapy involve higher risk, as do specific agents (Peterson, 1999).

Oral examination
Regular examination of the oral cavity enables detection of early signs of oral complications. Studies have shown that daily oral examination is rarely performed among nurses (Ezzone et al., 1993, Ganley, 1996, Nieweg et al., 1992). It has been recommended however, that the oral cavity should be examined and observations documented daily for early detection of oral manifestations. Also, changes should be recorded as soon as they are observed. For monitoring of efficacy and side effects, daily examinations should be conducted by professional staff (Beck, 1979, Heals, 1993, Holmes and Mountain, 1993, Yeager et al., 2000). However, there is a lack of knowledge about how patients receiving radio- or chemotherapy experience oral examination.

Oral hygiene procedures
Graham et al (Graham et al., 1993) found that the contents of information given to patients were inconsistently documented. According to Larson et al (Larson et al., 1998), patients are not taught on a routine basis how to care for the mouth. Several types of advice have been published on the management of oral hygiene (Barker, 1999, Holmes, 1998, Lunn, 1997, Lunn, 1998, Plevová, 1999, Raber-Durlacher, 1999). However, there is a lack of scientific evidence of the effects of recommended oral hygiene procedures (Plevová, 1999). Oral hygiene has been considered as a basic measure (Plevová, 1999) and some studies have demonstrated a reduction of oral complications after introduction of oral hygiene procedures including frequent tooth brushing (Beck, 1979, Borowski et al., 1994, Ellegaard et al., 1989, Graham et al., 1993, Hickey et al.,
1982, Karthaus et al., 1999, Levy-Polack et al., 1998). Mechanical plaque control may reduce the risk of mucositis progression (Bavier, 1990, Schubert et al., 1999). It has been recommended that oral hygiene procedures should be performed at least 3 to 4 times/day and that an oral care plan should accompany the patient’s general care plan (Beck and Yasko, 1993, Bonnaure-Mallet et al., 1998, Peterson, 1992).

In addition to dental hygiene care, the oral mucosa and the lips need to be kept moistened (Schubert et al., 1999). Among the available agents, none has been shown to be efficacious for prevention or healing mucositis, even though several agents have been investigated. Dental treatment and oral hygiene procedures still have an important role in the prevention and treatment of mucositis (Kowanko et al., 1998, Peterson, 1999, Plevová, 1999, Schubert et al., 1999, Wilkes, 1998).

Treatment for the relief of mouth dryness also includes thorough oral hygiene, saliva substitutes, and topical fluorides to prevent dental caries (Jansma, 1991, Peterson, 1992). Patients suffering from pain may be recommended topical analgesic agents, severe pain may even require continuous morphine treatment (Wilkes, 1998). A systematic approach based on written instructions is necessary to achieve uniformity in oral care. There are no studies of patient attitudes to oral hygiene instruction.

To sum up, a lot of research has been performed on the prevention and treatment of oral mucositis and prevention of infections. However, very little is known about patient attitudes to examination and information on oral hygiene and how often such actions are performed. There is also a lack of knowledge about the referral pattern to dentistry for patients with cancer.

**Oral self-care**

Oral self-care is important for the prevention of oral diseases like dental caries and periodontal disease. For patients treated with chemotherapy or radiotherapy, it is also important to prevent oral mucositis, infections and to relieve mouth dryness. Most oral hygiene procedures are possible to perform as self-care, and an adequate oral self-care program may facilitate compliance (Larson et al., 1998). To comply with comprehensive procedures may be bothersome, especially when suffering from a severe disease, and patients may need professional support (Kaplan et al., 1993). Nurses are in charge of supportive facilitation of the patient’s knowledge and self-care activities (Larson et al., 1998), and this needs to be performed in co-operation with dental hygienists.

There is lack knowledge of the extent of cancer patient compliance with oral hygiene procedures.
Documentation of oral status and oral care

A number of studies have demonstrated serious deficiencies in nursing documentation (see Ehrenberg (2000) for a review (Ehrenberg, 2000). In addition, the oral cavity seems to be a neglected area of nursing care and documentation on oral care is often lacking, suggesting a low priority for oral care (Ehrenberg and Ehnfors, 2001, Oneschuk et al., 2000, Robins Sadler et al., 2000). In a study of medical records Epstein and Gangbar reported that oral lesions were noted for 56% of the patients (Epstein and Gangbar, 1987). However, Sonis and Kunz (Sonis and Kunz, 1988) found notes on oral problems only among 13% of their patients.

Very little is known about the documentation of oral symptoms and oral care among oncology nurses.

The rationale for the study

There is still a lack of knowledge concerning patient experiences of a variety of oral symptoms developing over a period of intense treatment, and how these oral symptoms influence health-related quality of life. In order to provide adequate oral care, it is necessary to have knowledge about a healthy mouth, signs and symptoms of oral diseases and an attitude that oral health and oral care is of importance. Little is known about how often patients are referred to dentistry before the start of medical treatment and if oral care is provided and documented properly. In addition, knowledge about patient attitudes to oral care and compliance with advice may facilitate the implementation of adequate oral care procedures.
AIMS

The general aim of this thesis is to study several aspects of oral status, oral health and its relation to quality of life, and oral care among patients treated with radiotherapy or chemotherapy.

The following research questions will be penetrated:

♦ What characterises patients’ experiences of their oral status during radiotherapy for head and neck cancer or chemotherapy for haematological malignancies? To what extent do patient experiences agree with the occurrence of oral complications as assessed by professional staff? (Study I)

♦ Are there any relations between patient experiences of oral symptom and their perceived health-related quality of life? (Study II)

♦ What education in oral care, self-rated knowledge about oral care and attitudes to oral care characterise nursing staff in charge of patients with haematological malignancies, head and neck cancer or small cell lung cancer? Are there any differences between nurses and enrolled nurses? (Study III)

♦ What types of oral care are performed by nursing staff in charge of patients with haematological malignancies, head and neck cancer or small cell lung cancer? Are there any differences between nurses and enrolled nurses? (Study III)

♦ To what extent are patients with haematological malignancies, head and neck cancer or small cell lung cancer referred to dentistry before the start of medical treatment? (Study V)

♦ What characterises patient experiences of information on oral complications, examination of the oral cavity and oral hygiene information and instruction? (Study IV)

♦ What attitudes do patients have to oral examination and oral hygiene during cancer treatment. Are there any differences in attitudes to oral care between nursing staff and patients? (Study III, IV)

♦ To what extent do patients comply with instructions on oral care? (Study IV)

♦ To what extent is information about oral signs, symptoms and oral care noted in the medical records of patients with haematological malignancies, head and neck cancer or small cell lung cancer? (Study V)
MATERIAL AND METHOD

Design
Descriptive, comparative and correlational designs were used for the studies as displayed in Table 1. A prospective longitudinal design with repeated measures was used in Studies I and II. Studies III and IV are cross-sectional and the chart review in Study V is retrospective (Table 1).

Table 1. Design and data collection methods used in Studies I - V.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Data collection method</th>
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<tbody>
<tr>
<td>I</td>
<td>Prospective descriptive and correlational with repeated measures</td>
<td>Self-recording, physical examination and saliva tests</td>
</tr>
<tr>
<td>II</td>
<td>Prospective descriptive and comparative with repeated measures</td>
<td>Self-recording, physical examination and saliva tests</td>
</tr>
<tr>
<td>III</td>
<td>Cross-sectional, descriptive and comparative</td>
<td>Semi-structured interview with hospital staff</td>
</tr>
<tr>
<td>IV</td>
<td>Cross-sectional, comparative</td>
<td>Semi-structured interview with patients</td>
</tr>
<tr>
<td>V</td>
<td>Retrospective, descriptive</td>
<td>Chart review</td>
</tr>
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Subjects
From August 1998 until August 1999, a convenience sample of 52 consecutive patients was eligible for the prospective study including repeated measures. The final sample consisted of 41 patients (79%), admitted to a university (n = 26) or a regional hospital (n = 15) to receive radiotherapy for head and neck cancer (n = 18) or chemotherapy for haematological malignancies (n = 23), (Studies I, II, IV).

Among the 18 patients with head and neck cancer, a total of 11 patients received radiotherapy in 2 Gy fractions / day, with a total dose of 50 Gy (n = 2), 66 Gy (n = 5) or ≥ 70 Gy (n = 4). Seven patients received radiotherapy in 1.2 Gy sections twice daily. This was done 5 days a week for 5 – 7 weeks depending on the amount of radiation to be given. Seven patients also received chemotherapy of moderate intensity.

Among patients with haematological malignancies, 14 patients received chemotherapy of moderate intensity: intravenous treatment in doses usually inducing mild or moderate bone marrow
suppression, and 9 received therapy of intensive intensity: intravenous treatment in doses regularly inducing severe bone marrow suppression.

All nurses (n = 98) and enrolled nurses/nursing assistants (referred to in Study III as enrolled nurses) (n = 51), who worked with patients with haematological malignancies, head and neck cancer or small cell lung cancer at a university hospital and a regional hospital, were approached for interviews during the spring of 1997, and 92% (nurses n = 90, enrolled nurses n = 47) participated (Study III).

In Study V, all records on patients with haematological malignancies, head and neck cancer and small cell lung cancer (n = 202) at a university hospital and a regional hospital in the years 1990 – 1992 were eligible for a chart review. A total of 188 records (93%) were reviewed.

Number of subjects and characteristics regarding gender, age and diagnosis are presented in Table 2. Further details on subjects and non-participants are presented in the methods section of each of the studies.

**Table 2. Subject characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Studies I, II, IV (patients)</th>
<th>Study III (staff)</th>
<th>Study V (patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of eligible subjects</td>
<td>52</td>
<td>149</td>
<td>202</td>
</tr>
<tr>
<td>Number of participants (%)</td>
<td>41 (79)</td>
<td>137 (92)</td>
<td>188 (93)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Female (%)</td>
<td>16 (39)</td>
<td>130 (95)</td>
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<tr>
<td>Male (%)</td>
<td>25 (61)</td>
<td>7 (5)</td>
<td>115 (61)</td>
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<tr>
<td>Diagnosis</td>
<td></td>
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<tr>
<td>Haematological malignancies (%)</td>
<td>23 (56)</td>
<td>-</td>
<td>118 (63)</td>
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<tr>
<td>Head and neck cancer (%)</td>
<td>18 (44)</td>
<td>-</td>
<td>46 (24)</td>
</tr>
<tr>
<td>Small cell lung cancer (%)</td>
<td>-</td>
<td>-</td>
<td>24 (13)</td>
</tr>
</tbody>
</table>
**Instruments**

*Experiences of oral symptom*

Experiences of oral symptoms were rated on 100-mm visual analogue scales with end-points “no oral discomfort” – “worst imaginable oral discomfort”. The questions concerned the following ten conditions of the oral cavity: pain, mouth dryness, salivary viscosity, ability to talk, ability to perform oral hygiene, dysphagia, taste alterations, the condition of lips and gingiva, and the feeling of a clean mouth. The form was a revised version of that presented by Kosac et al (Kosac et al., 1996) (Studies I, II, IV). All oral symptoms were summarised at each assessment to an Oral Symptom Summary Score (OSSS) to facilitate comparisons (Study II). The OSSS peak score was defined as the highest score for each patient during the assessment time (Study IV). Higher scores indicate more intense symptoms.

*Mucositis*

Mucositis was assessed by the Oral Mucositis Index (OMI) (Schubert et al., 1992). The OMI assesses atrophy, erythema, edema and pseudomembrane/ulceration in eleven regions of the oral cavity, each rated from 0 (normal) to 3 (very severe). The total score range is 0 – 102 (Studies I, II, IV).

*Salivary secretion rate*

Salivary secretion was assessed by collection of resting whole saliva as well as stimulated saliva. Resting whole saliva was collected by having the patient drivel in a graduated glass during 5 min. Saliva was stimulated by chewing on 1 g of paraffin and collected in a graduated glass during 5 min. The secretion rate was determined as ml per min. Normal flow rate of resting whole saliva is ≥ 0.3 ml/min and normal flow rate of stimulated saliva is ≥ 1 ml/min. A resting flow rate of < 0.1 ml/min and a stimulated flow of < 0.7 ml/min are generally indicative of hyposalivation (Tenovuo and Lagerlöf, 1994) (Study I).

*Dental caries*

Dental caries observation was performed at baseline and expressed as decayed and filled permanent surfaces (DFS). For patients who had visited hospital dentistry, supplementary details were gathered from the dental records (Studies I, II, IV).

*Gingival condition*

Gingival condition was assessed visually on the buccal surfaces of the teeth included in the Community Periodontal Index (CPI) (WHO, 1997), using a four-point scale (normal, mild, moderate, severe) at baseline and at the end of the study (Study I).
Oral hygiene
Oral hygiene was assessed visually and rated as a global score ranging from excellent, rather good to poor or very poor. Penlight and mirror was used at all assessments (Study I).

Body Weight
Body weight was measured on a digital balance at baseline and at the end of the study (Study I).

Interview with patients
A semi-structured format was employed for the patient interviews. These were based on an interview guide consisting of a 41-item questionnaire including open-ended questions covering the following areas of patient experiences: oral hygiene habits, and dental visits before diagnosis and during cancer treatment, information on oral complications and oral hygiene and instructions in oral hygiene, experiences of oral complications and oral hygiene procedures, frequency of oral examination performed by hospital staff, patient attitudes to oral examination, and questions on oral hygiene and ability to eat and drink during cancer treatment. This assessment also included patient judgements of the influence of oral status on health-related quality of life, assessed by two questions: To what extent have the oral symptoms had an impact on your quality of life? Have the oral symptoms been a hindrance in your everyday life? (Studies II, IV).

Health-related quality of life, HRQOL
HRQOL was assessed by the European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993). This is a 30-item instrument composed of multi-item scales and single items that are supposed to reflect health-related quality of life. It includes five functional scales [physical (PF), role (RF), cognitive (CF), emotional (EF) and social (SF)], three symptom scales (fatigue, pain, nausea and vomiting), and a global health and quality of life scale (QL). Remaining single items assess symptoms that are frequently reported by cancer patients, such as dyspnoea, loss of appetite, sleep disturbances, constipation and diarrhea, and an item on the financial impact of disease and treatment. Responses to all scales and single items are given on four- or seven-point Likert scales. The time window is "the previous week" (Study II).

The EORTC QLQ-H&N35 was employed to tap aspects of quality of life specific to head and neck cancer (Bjordal et al., 1994a, Bjordal et al., 1999, Sprangers et al., 1993). This is a 35-item module composed of seven multi-item scales (pain, swallowing, senses, speech, social eating, social contact and sexuality) and eleven single items. With the exception of five items (use of pain killers, nutritional supplements, feeding tube, weight loss and weight gain), all scales and items have
four-point Likert scales. Remaining single items have a dichotomous response format (yes /no). The time window is “the previous week” (Study II).

**Interview with nurses and enrolled nurses**
A semi-structured interview format was employed based on a 43-item questionnaire including open-ended questions covering the following areas: basic and continuing education in oral care, information on and estimated frequency of oral complications, examination of the oral cavity, documentation on oral care, oral care routines, attitudes to oral care, co-operation with dentistry, and demographic data. Self-rated knowledge in specific areas of oral care was rated on 100 mm visual analogue scales with end-points “non existent – excellent”. Higher scores indicate better knowledge (Study III).

**Oral self-care**
Daily self-recording of oral hygiene self-care procedures was performed on a form with columns for various kinds of oral hygiene products and one column for dates, to be completed each time a product was used during the day. The form was a revised version of that presented by Kosac et al (Kosac et al., 1996) (Study IV).

**Chart review**
A chart review protocol was developed for this study with a form including information about diagnosis, length of stay in hospital, type of antineoplastic treatment, drugs, notes made by physicians and nurses on oral signs and symptoms and oral care performed at the ward, referral to dentistry and demographic data (Study V).

**Procedure**
Patients in Studies I, II and IV were given written and verbal information at the invitation to participate. All participants gave their written consent. Baseline was defined as the assessments before the start of radiotherapy or the second/third chemotherapy cycle, respectively. At that time, interview questions were asked regarding oral hygiene and dental visits before diagnosis, and the oral cavity was examined with regard to gingival condition, dental caries, oral hygiene and mucositis. Stimulated and resting whole saliva was collected and body weight was measured. Patients completed the VAS questionnaire concerned with their experience of oral conditions and filled in the HRQOL instrument. The form for daily self-recording of oral hygiene procedures was handed out. The same observer performed the baseline assessment and the final assessment throughout.
Patients were examined regularly by one of two observers at the clinic or in their homes at every ten Gy increase of radiotherapy (head and neck), or once a week during the chemotherapy cycle (haematological malignancies). Mucositis and oral hygiene were assessed, resting whole saliva was collected and patients completed the VAS questions. The self-recording form on oral hygiene was collected and a new one was handed out. At 30 Gy (head and neck) or after two weeks (haematological malignancies), patients also completed the EORTC QLQ-C30 and the EORTC QLQ-H&N35 questionnaires (head and neck).

After completion of radiotherapy or the chemotherapy cycle, assessments identical to those at baseline were repeated. In addition, there was a final interview as described earlier. Data on diagnosis, dental and medical treatment and leukopenia were retrieved from the dental and medical records.

In addition, patients given radiotherapy were interviewed one month post treatment when they also completed the VAS questions concerned with experiences of oral status. Patients receiving radiotherapy were interviewed by telephone one month after treatment using mainly the same questions as at the end of treatment. At that time, they also completed the EORTC QLQ-C30, the EORTC QLQ-H&N35 and the VAS questionnaire, which had been mailed to patients.

Nursing staff was given written information when invited to participate in Study III. For those who agreed to participate, the head nurse arranged a time for a personal interview. The interviews took place at work and lasted for 20 - 30 minutes. The interviewer wrote down the respondents’ replies.

One observer reviewed all charts in Study V. The records were examined from the time of cancer diagnosis and for at least one year.

**Analysis and statistical procedures**

Data from the chart review and interviews were categorised according to content similarities and differences. In the analysis of the patient interviews, notes were carefully read to determine categories. Statements were then categorised by the first author. A second assessor was provided with all statements and sorted these, using the same categories. Responses regarding the impact of oral symptoms on quality of life were categorised into great, some and no influence. The response category “irrelevant” was used for patients reporting no oral symptoms in the interview. Replies to the question on oral symptoms as a hindrance were categorised into yes, no and irrelevant.

Linear 0-100 transformations were performed on each item of the EORTC QLQ-C30 and the EORTC QLQ-H&N35. Higher scores on the functional QLQ-C30 scales, and on the global health status quality of life scale indicate a higher quality of life, whereas higher scores on symptom scales, the multi-item QLQ-H&N35 scales and single items indicate more intensive symptoms.
Data were presented as descriptive statistics by means of cross-tabulation and frequency tables. A p-value $\leq .05$ was considered statistically significant if not stated otherwise. The statistical methods used for analysis are presented in Table 3. Detailed descriptions are presented in the methods section of each of the studies.

**Table 3. Statistical methods**

<table>
<thead>
<tr>
<th>Study</th>
<th>Statistical method</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Repeated measures analyses of variance (ANOVA) using Fisher’s PLSD test for post hoc comparisons. Friedman analysis of variance by ranks, Mann-Whitney U-test, paired t-test, Wilcoxon signed rank test, Spearman rank correlations</td>
</tr>
<tr>
<td>II</td>
<td>Repeated measures analyses of variance (ANOVA) using Fisher’s PLSD test for post hoc comparisons. Friedman analysis of variance by ranks, t-test, Pearson correlation coefficient. For correlations computed for each single oral symptom, a p-value of $&lt; 0.01$ was regarded as statistically significant</td>
</tr>
<tr>
<td>III</td>
<td>$\chi^2$ test, unpaired t-test or two-way analysis of variance. The Fischer PLSD-test was used for post hoc testing</td>
</tr>
<tr>
<td>IV</td>
<td>$\chi^2$ test, t-test</td>
</tr>
<tr>
<td>V</td>
<td>Pearson’s product-moment correlation, two-tailed t-test (unpaired), Mann-Whitney U test, ANOVA and $\chi^2$ test</td>
</tr>
</tbody>
</table>

**Ethical considerations**

All data were treated confidentially. Permission for each study was obtained from the medical directors at each department and all studies were approved by the Research Ethics Committee of the Faculty of Medicine at Uppsala University
RESULTS

**Patient experiences of oral symptoms and the occurrence of oral complications**

Study IV demonstrated that 85%, including all patients receiving radiotherapy (n = 18) and 17 patients receiving chemotherapy (out of n = 23), reported that they had experienced oral symptoms. Among those, 42% (n = 17) stated that they had received some help with their oral symptoms. Patients receiving radiotherapy reported significantly more oral symptoms (OSSS peak value 555 ± 246) and higher mucositis scores (OMI peak value 29.4 ± 11.8) than patients receiving chemotherapy (OSSS 142 ± 105) (OMI 6.8 ± 8.7) (t = 7.2, 7.1; df 39; p < .001).

*Patients receiving radiotherapy for head and neck cancer*

In Study I, patients with head and neck cancer experienced a significant increase in oral symptoms at the end of treatment compared to the start of radiotherapy. One month post treatment, several oral symptoms were still elevated compared to baseline (Fig. 1, 2).

![Graph](attachment:image.png)

**Fig. 1.** Reports of oral symptoms related to saliva among patients receiving radiotherapy for head and neck cancer (symptom ratings using visual analogue scale).
Fig. 2. Reports of oral symptoms related to oral mucosa among patients receiving radiotherapy for head and neck cancer (symptom ratings using visual analogue scale).

The oral mucositis scores showed a significant increase over time (2.2 ± 2.5 at baseline, 28.8 ± 13.5 at the end of treatment) (F = 24.5; df 7/84; p < .001). All patients had at least one sign of mucositis. Oral ulcers occurred in 17% of patients at baseline and this figure increased to 100% at the end of treatment. The resting whole salivary secretion rate decreased significantly after 10 Gy, followed by a slow recovery (.47 ± .41 at baseline, .27 ± .28 after 10 Gy, .40 ± .51 at the end of treatment) (F = 2.3; df 7 /77; p < .05). The secretion of stimulated saliva decreased significantly from baseline (1.8 ± 1.0) until the end of treatment (1.0 ± 1.0) (t = 2.4; df 13; p < .05) and so did body weight (69.8 ± 15.3 vs. 66.3 ± 13.6) (t = 3.7; df 17; p < .01). The occurrence of gingivitis increased significantly from baseline (.25 ± .29) to treatment termination (.67 ± .51) (z = 2.95; p < .01).

With the exception of mouth dryness and dysphagia, there were significant correlations between mucositis scores and all oral symptoms rated by patients (Rho = .49 to .68; p < .05). Significant negative correlations were demonstrated between the resting salivary secretion rate and experience of a dry mouth from the administration of 10 Gy throughout radiotherapy (Rho = -.56
to -.86; p < .05). In addition, there were significant negative correlations between the resting salivary secretion rate and salivary viscosity at 30 and 40 Gy ($R_{\theta} = -.50 -.63$, p < .05) (Study I).

**Patients receiving chemotherapy for haematological malignancies**

Patients with haematological malignancies evidenced a different pattern of changes. Oral symptoms tended to increase somewhat from baseline to two weeks later, followed by an improvement. However, none of these changes were significant with the exception of taste alteration, which peaked one week after baseline and decreased significantly three weeks after the start of treatment (Fig. 3, 4).

![Fig. 3. Reports of oral symptoms related to saliva among patients receiving chemotherapy for haematological malignancies (symptom ratings using visual analogue scale).](image-url)
Fig. 4. Reports of oral symptoms related to oral mucosa among patients receiving chemotherapy for haematological malignancies (symptom ratings using visual analogue scale).

Oral mucositis scores paralleled patient reports of oral symptoms with a significant increase two weeks after baseline (1.8 ± 2.3 at baseline, 5.8 ± 9.4 after 2 weeks) (F = 3.4; df 3/60; p < .05). At baseline, 57% of the patients evidenced some signs of mucositis, and at most 86% had at least one such sign. Oral ulcers occurred in 4% of patients at baseline and this increased to 22% during the chemotherapy cycle. The secretion rates of stimulated and resting whole saliva did not change significantly during the chemotherapy cycle. The gingivitis score increased significantly from baseline (.18 ± .35) until the start of the next cycle (.30 ± .47) (z = 2.62; p < .01), and so did body weight (75.5 ± 14.0 vs. 76.5 ± 13.9) (t = 2.4; df 22; p < .05) (Study I).

Significant correlations were demonstrated between the oral mucositis scores and the experience of lip dryness after one and two weeks (Rho = .56 to .62; p < .01). At the assessment after two weeks, the resting salivary secretion rate was negatively correlated with the experience of a dry mouth (Rho = -.72; p < .01), and with salivary viscosity (Rho = -.59; p= < .01). After three weeks the resting salivary secretion rated correlated with dry mouth, salivary viscosity, ability to perform oral hygiene, taste alteration and the feeling of a clean mouth (Rho = -.48 to -.62; p < .05) (Study I).
Oral symptoms and health-related quality of life (HRQOL)

Patients receiving radiotherapy for head and neck cancer

According to patient ratings on the functional HRQOL scales, quality of life tended to decrease over time (Fig. 5).

Fig. 5. Men values on functional EORTC QLQ-C30 scales among patients receiving radiotherapy for head and neck cancer (PF physical functioning, RF role functioning, EF emotional functioning, CF cognitive functioning, SF social functioning, QL global health and quality of life).

Mean symptom scores increased until the end of treatment and so did the specific scales for patients with head and neck cancer, although these changes did not always reach statistical significance (Fig. 6). The same pattern was seen for oral symptoms. Thus, an increase of the radiation dose was accompanied by a lower quality of life (Study II).
Fig. 6. Mean values on EORTC QLQ-H&N35 functional scales among patients receiving radiotherapy for head and neck cancer.

At the end of treatment when oral symptoms were most intense, patients who reported that their oral symptoms had a great influence on their HRQOL (n = 10, 56%) had significantly lower scores for global health status and all functional scales but cognitive functioning (15.0 to 64.6) compared to those who reported some or no such influence (64.5 to 89.1) (p < .05). Those ten patients who reported a great influence also had significantly higher OSSS scores (635 ± 209) than those who stated that oral symptom had some or no (n = 8, 44%) such influence (353 ± 198) (t = 2.9; df 16; p < .01). Among the 16 patients who completed the EORTC QLQ-H&N35, there were 8 who reported that their oral symptoms had a great influence on their HRQOL. They reported higher symptom scores than those who reported some or no such influence on four of the seven multi-item scales, and on two of the six single items on the EORTC QLQ-H&N35 at the end of treatment when oral symptoms were most intense. One month after treatment when oral symptoms had decreased, no significant differences could be demonstrated between these groups in quality of life scores or oral symptoms. However, six patients (33%) still reported that their oral symptoms had a great influence on their HRQOL (Study II).
In Study IV, almost all patients (n = 17, 94%) complained about oral symptoms and 15 had been unable to eat as usual. Oral symptoms had had a very large or large influence on eating for 9 patients. Only one patient who reported eating difficulties stated that the oral symptoms were of no importance, but that taste alteration was the main problem.

There were statistically significant negative relationships between the OSSS total score and the EORTC QLQ-C30 global health status and all functional scales but cognitive functioning at the end of the treatment (r = -.47 to -.65; p < .05). One month after treatment there were significant negative correlations between the OSSS total score and physical functioning, role functioning and the global health and quality of life scale (r = -.53 to -.65; p < .05) (Study II).

Patients receiving chemotherapy for haematological malignancies

For this group of patients, there were no significant changes over time regarding HRQOL with the exception of role functioning which decreased after two weeks and increased at the end of the cycle (Fig. 7).

![Fig. 7. Mean values on EORTC QLQ-C30 functional scales among patients receiving chemotherapy for haematological malignancies (PF physical functioning, RF role functioning, EF emotional functioning, CF cognitive functioning, SF social functioning, QL global health and quality of life).]
Similarly, symptoms and single items did not change with the exception of fatigue, which increased after two weeks and decreased at the end of the cycle. The OSSS scores increased up to two weeks and then decreased though these changes did not reach statistical significance (Study II).

At the end of the chemotherapy cycle, only one patient reported that oral symptoms had a great influence on HRQOL, 5 patients (22%) that it had some influence, 12 patients (52%) no influence, and 5 patients reported no oral symptoms. Three patients stated that their oral symptoms had been a hindrance in their everyday life, mostly for social reasons (Study II).

After two weeks, there were statistically significant negative relationships between the OSSS total score and the EORTC QLQ-C30 global health status and all functional scales but role and emotional functioning (r = -.58 to -.78; p < .01). At the end of the chemotherapy cycle, there were significant negative correlations between the OSSS and all functional scales but emotional functioning (r = -.46 to -.76; p < .05) (Study II).

**Eating problems: both groups of patients**

In Study IV, significantly more patients receiving radiotherapy (89%) reported difficulties to eat and drink as usual compared to those receiving chemotherapy (39%) \( (\chi^2 = 10.5; \text{df} 1; p < .01) \). Among all patients, 39% (n = 16) reported that they were able to eat as usual and 17% (n = 7) had experienced nausea and taste alteration as a hindrance. Sixteen patients reported that their oral symptoms had a very large or large influence on their ability to eat, and three reported some influence. The remaining six patients with eating difficulties reported nausea and taste alterations.

Fifteen percent (n = 6) reported difficulties to eat but that they did not mention this to hospital staff – “it was not too bad”. The respondents who reported eating difficulties (n = 25) had higher OSSS scores (456 ± 268) than those (n = 16) without eating problems (117 ± 98) (t = 4.8; df 39; p < .001). There was also a significant difference in mucositis scores (23.1 ± 15.7 vs. 6.8 ± 6.5) (t = 3.9; df 39; p < .001). The treatment and advice received for eating difficulties concerned nasogastric feeding (n = 4), nutritional supplements (n = 6), dietary advice (n = 2) and preventive local anaesthesia (n = 4). Among the 25 patients who reported eating difficulties, 13 reported drinking difficulties as well.

**Education and knowledge among nursing staff**

None of the nurses and only four of the enrolled nurses (3% in all) reported that they had received substantial education in oral care. Twenty-three nurses and six enrolled nurses (21%) reported that they had not received any education in oral care. Among the remaining 76%, 19% did not remember, and 57% had received some education in oral care during their basic training. Only 7% of all respondents stated that they had acquired sufficient knowledge in oral care during their basic
training. An additional 5% stated that they had acquired enough knowledge of oral care in general but not for patients on chemotherapy or radiotherapy. A total of 13% of all respondents had attended a regular continuing education course in oral care, and 32% had not received any continuing education in oral care (29 nurses, 15 enrolled nurses). Attendees assigned a higher priority to oral care than did remaining staff. A need for continuing education in oral care was stated by 86% (Study III).

The self-rated knowledge was poorest on fluorides, oral signs and symptoms and examination of the oral cavity and highest on tooth brushing and cleaning dentures. Nurses estimated their knowledge on pain relief to be significantly better (7.3 ± 1.8) than did enrolled nurses (5.2 ± 2.4) (t = 5.5; df 134; p < .001). However, enrolled nurses estimated their knowledge to be significantly better than did nurses on cleaning dentures (8.4 ± 1.6 vs. 7.0 ± 2.1) (t = 3.9; df 134; p < .001) and examination of the oral cavity (6.4 ± 2.2 vs. 5.7 ± 1.9) (t = 2.1; df 135; p < .05) (Study III).

**Attitudes to oral care**

According to Study III, all staff thought that oral care was important for patients with these cancers. However, 18% felt uncomfortable to ask their patients regarding oral hygiene. There was a significantly higher proportion of enrolled nurses (28%) than nurses (12%) who felt uncomfortable ($\chi^2 = 5.1; \text{df } 1; p < .05$). Those who performed oral examination frequently felt more comfortable to discuss oral hygiene that those who did not ($\chi^2 = 11.5; \text{df } 2; p < .01$). A total of 45% objected to examining the oral cavity and stated patient integrity as the main reason. Those who objected to performing oral examination felt significantly more uncomfortable to discuss oral hygiene than those who did not ($\chi^2 = 7.7; \text{df } 1; p < .01$). Discomfort in examining the oral cavity was reported by 28%. More enrolled nurses (38%) than nurses (22%) felt uncomfortable at oral examinations ($\chi^2 = 4.0; \text{df } 1; p < .05$).

Hospital staff had asked about oral hygiene according to 25% (n = 10) of the patients. Most patients (n = 27, 66%) considered it to be all-right if hospital staff asked about oral hygiene, and an additional 9 (22%) thought it would be very good. Only 4 patients (10%) had no opinion on this matter and one patient did not want the hospital staff to ask about oral hygiene, but that it was enough if dental staff did so. A total of 29 patients (71%) thought it was all-right if hospital staff examined their oral cavity and an additional 9 (22%) considered it to be very good. Three patients did not want this procedure to take place (Study IV).
Oral care

Referrals to dentistry

A total of 167 patients (88%) received active treatment for their cancer, and 73 of these (44%) were referred to dentistry before the start of treatment. An additional 19 (11%) were referred later for acute complications. Among the 94 patients who were not referred to dentistry before the start of their treatment, 8 patients were referred later for consultation (Study V).

In Study V it was found that 112 patients had received chemotherapy and 50 patients had received radiotherapy towards the oral cavity. Some of the patients had received a combination of those treatments or radiotherapy towards other sites, surgery or various combinations. Of the ten patients who received intensive chemotherapy, 7 were referred before the start of treatment and 3 were referred for acute complications. Twenty-four (34%) of the 70 patients who received moderate intensity chemotherapy were referred to dentistry before the start of treatment, and 10 (14%) were referred for acute complications. Corresponding figures for the 32 patients receiving mild intensity chemotherapy were 3 (9%) referrals before the start of treatment and 6 (19%) acute referrals. A total of 53 patients (47%) had visited dentistry.

Of the 50 patients who received radiotherapy directed towards the oral cavity, 45 (90%) were referred to dentistry before the start of treatment, and two patients (4%) were referred for acute complications (Study V).

There was a statistically significant relation between referral to dentistry before the start of treatment and notes on oral problems in the patient records ($\chi^2 = 15.1; \text{df } 1; p < .001$). However, 43 patients (43%) with oral problems documented before or during their medical treatment were not referred to dentistry before the start of treatment. Sixteen of them were later referred for acute problems (Study V).

In the interview in Study IV, all patients who received radiotherapy reported that they had visited hospital dentistry. Among patients receiving chemotherapy, 11 (48%) had done so. Most patients ($n = 27$) were referred to hospital dentistry in accordance with routines. The main reason for referral was examination before the start of medical treatment, which was true for 86% of those who visited hospital dentistry.

A total of 54% of the staff in Study III reported that patients were routinely referred to dentistry before the start of medical treatment. A majority reported that they received sufficient help from dentistry, which was true for more nurses (79%) than enrolled nurses (51%). Repeated contacts with dentistry were reported by 42%.
Information on oral complications
Nurses stated that they informed patients that oral complications might result from cancer treatment significantly more often than did enrolled nurses ($\chi^2 = 54.4$; df 2; $p < .001$). Among the nurses, 69% always informed patients on oral complications (Study III). Information on oral complications had been received by 85% of the patients in Study IV ($n = 35$), including all those receiving radiotherapy ($n = 18$), mostly verbally (94%). Mostly dental staff performed this (61%).

Examination of the oral cavity
According to the staff in Study III, daily examination of the oral cavity was performed by 6% and 19% never performed oral examination. It was most common to examine the patient occasionally, usually if the patient indicated some complaint. Nurses examined patients orally significantly more often than did enrolled nurses ($\chi^2 = 20.8$; df 2; $p < .001$). Only 10% of the respondents reported that they used a specific system for oral examination. However, 61% considered that a more systematic examination would be useful.

Out of the 41 patients in Study IV, 21 (51%) reported that no hospital staff had examined their oral cavity. Patients receiving chemotherapy were over-represented in this group. Among patients receiving radiotherapy ($n = 18$), 16 were examined by a physician usually at the weekly head and neck conference, and one had been examined by a nurse. Among patients receiving chemotherapy ($n = 23$), three had been examined by a physician and one also by a nurse. Dental staff had examined an additional 10 patients (24%), but no hospital or dental staff had examined 11 patients (27%) and among these, 9 were inpatients. In addition, 9 of the 11 patients who had not been examined reported that they had oral symptoms during treatment.

Oral hygiene procedures
Information on oral hygiene was given to patients according to 36% of staff in Study III, usually focused on encouragement of thorough cleaning of the teeth. A majority never instructed patients on how to perform thorough oral hygiene procedures.

All Study IV-patients receiving radiotherapy had received information on oral hygiene, which was significantly more than those receiving chemotherapy (56%). A total of 31 patients (76 %), including all patients receiving radiotherapy, had received information on oral hygiene. Ten patients (24%) received no information and seven of these were outpatients. In 73% of the cases, dental personnel gave the information.

A total of 21 patients (51%), including all those who had received radiotherapy had also received practical instruction in oral hygiene, given mostly by a dental hygienist. Patients who had
received instruction in oral hygiene brushed their teeth significantly more often (2.6 ± 0.8 /day) than those who had not received instruction (2.0 ± 0.7) (t = 2.4; df 39; p < .05) (Study IV).

In Study III, most of the staff (97%) stated that they assisted patients with their oral care if necessary. When this occurred it was to a great extent on initiatives from the staff. The nurses often delegated the oral care to enrolled nurses. In Study IV, 59% of the patients (n = 24) reported that their oral hygiene procedures had been satisfying during treatment and 41% reported some difficulties with their oral hygiene, because of extensive procedures, pain and nausea. No patient reported that they had needed help with their oral hygiene procedures. In Study I, it was demonstrated that oral hygiene on the whole was good or excellent during the treatment period.

Those 18 patients who were treated with radiotherapy for head and neck cancer were interviewed one month after treatment as well. The oral hygiene procedures had been satisfying for 15 patients (83%), but 3 still reported some difficulties (Study IV).

**Oral self-care**
The majority of patients (68%) brushed their teeth twice a day. During treatment, patients used toothpaste significantly less often than they brushed their teeth, which may be due to the taste and composition of toothpaste. All patients receiving radiotherapy were informed and instructed to clean their oral mucosa 4 times daily and in addition to use antifungal prophylaxis. Twelve patients did so ≥ 3 times/day. The same routines were recommended for chemotherapy patients when they were isolated during the leukopenia period, which was true for three of six patients with leukopenia. Rinsing solutions and saliva substitutes were used 3 - 4 times daily during a short period of time (2 – 4 weeks) among patients receiving radiotherapy. No patient receiving chemotherapy used rinsing solutions or saliva substitutes frequently. Three of the patients receiving radiotherapy did not use fluoride daily, despite such a recommendation (Study IV).

**Documentation of oral status and oral care**
In study V, 167 patients (88%) received active treatment for their cancer. Physicians’ records contained notes on oral status for 136 (81%) of these patients and the notes concerned oral problems in 93 patients (56%). Corresponding figures for the nurses were 61 records (37%) with notes on oral status and 36 (22%) concerning oral problems. Among 21 patients given no active treatment there were notes on oral problems by physicians in 11 records. In the nurses’ records, there were notes on oral problems for four of these patients. There were no notes on oral care in any of the physicians’ records. In the nurses’ records, there were notes for 24 patients (14%).

A total of 84% of the nurses in Study III stated that they documented findings when there were status changes or problems in the oral cavity and 13% did so irrespective of specific problems. The enrolled nurses did not make notes but reported verbally to nurses.
DISCUSSION

General aspects
The aim of this thesis is to study several aspects of oral status, oral health and its relation to quality of life, and oral care among patients treated with radiotherapy or chemotherapy. The approach chosen was to focus on patient experiences of oral symptoms and on oral care as provided by several groups of professionals. The most interesting finding in the prospective study of patients receiving radio- or chemotherapy was that oral symptoms are related to HRQOL. These relationships were investigated by several methods, yielding a consistent pattern of results. Patients’ communication skills and possibilities to eat and drink as usual were compromised because of their oral symptoms. The oral cavity is neglected in health care, which creates unnecessary problems for patients. Patients had no objections against having their oral cavity examined or to discuss oral hygiene with hospital staff. It is urgent that nursing staff understand the importance of oral problems and their relation to HRQOL in order to provide adequate care. However, nursing staff reported that their knowledge and skills in oral examination and assessment was poor. In addition, they had objections against examining the oral cavity and to discuss oral hygiene and stated patient integrity as a reason for this, an attitude that was not shared by patients. Overall, the results illustrate the need for multidisciplinary collaboration in oral care.

Oral health, oral symptoms and oral complications
Reports of oral symptoms reflect patient opinion, and they are valid independently of the results of assessments by professional staff. Patient reports are valuable for communicating with patients and between nursing and dental staff. Previous research has shown that patients do not always report their oral symptoms (Bjordal et al., 1995, Persson, 1998, Wells, 1998) which may create problems in oral care. Persson et al reported that several oral complications were observed by staff, but the patients saw these as problems associated with the treatment that could not be avoided and therefore did not talk about them (Persson, 1998). In a study by Wells, patients regarded treatment-induced problems to be insignificant compared to those occasioned by the cancer disease itself (Wells, 1998). The present findings illustrate that patients experience several oral symptoms and that there is good agreement between patient reports and recordings by dental staff. Among patients receiving radiotherapy, there were significant correlations between mucositis scores and all aspects of oral symptoms beside mouth dryness and dysphagia. Mouth dryness and salivary viscosity correlated significantly with the resting salivary secretion rate. These relationships were less evident among patients receiving chemotherapy. However, there were correlations between mucositis scores and lip dryness and between the salivary secretion rate and several aspects of oral symptoms.
The oral symptom VAS used in the present study includes aspects such as difficulties to perform oral hygiene and a feeling that the mouth is not clean. These are never assessed in an index used by health care staff. The studied symptoms represent a variety of oral discomforts and all patients receiving radiotherapy and a major proportion receiving chemotherapy experienced such symptoms. The observation that patients receiving radiotherapy are more affected by oral symptoms than are chemotherapy patients is in agreement with earlier findings (Lunn, 1998, Sonis et al., 1999, Spijkervet et al., 1989). Patients with head and neck cancer have their tumours located in or in the vicinity of the oral cavity, which may create an additional influence on their experience of oral symptoms. The tumour itself may cause a variety of symptoms. All types of oral symptoms increased irrespective of the fact that patients were subjected to oral examination and oral care by dental staff regularly.

Since the occurrence of oral mucositis agreed with reports of oral symptoms, mucositis may be an important factor related to this type of discomfort (Bundgaard et al., 1993, Kuten et al., 1986, McGuire et al., 1998). Bundgaard et al reported that 73% of patients with head and neck cancer had mucositis and many also reported oral discomfort (Bundgaard et al., 1993). Kuten et al reported erythema in the mucosal surfaces among 45% of patients receiving radiotherapy, dysphagia was reported by 59% and soreness by 37% (Kuten et al., 1986). In a study by McGuire et al on patients with leukaemia, mucositis was expected to increase approximately 2 weeks after chemotherapy and so were patient rating of pain intensity (McGuire et al., 1998). For patients receiving chemotherapy in the present study, the resting salivary secretion rate was related to several oral symptoms and needs to be taken seriously. Some patients reported that they had received extensive information and advice but no measure gave sufficient relief. This illustrates that oral symptoms may be severe.

Patients receiving radiotherapy experience severe oral symptoms and need considerable support from dental as well as nursing staff. After treatment termination, when symptoms are at their peak, it is of great importance that the dental staff, who has sufficient knowledge to treat the oral symptoms, continues to see these patients. Mouth and lip dryness and salivary viscosity remained elevated in the present patients one month after treatment. This represents an important threat to the oral health since saliva is an important protector (Ekström, 2000, Jansma, 1991, Tenovuo and Lagerlöf, 1994). The patients also needs to continue treatment with fluoride to prevent dental caries (Jansma, 1991), a procedure which is not always sustained (Epstein et al., 1995). Repeated support from professional staff facilitates compliance, and nursing staff needs to improve their knowledge on fluorides.

A surprising finding was that the salivary secretion rate recovered at the end of treatment for patients receiving radiotherapy. Previous findings have shown a reduction of the resting salivary secretion rate among patients receiving radiotherapy (Eisbruch et al., 1999, Epstein et al., 1998,
Kuten et al., 1986). However, few patients were studied in the saliva test because some of them could not provide any saliva at the later assessments and did not want to participate for that reason. The limited time of five minutes to collect saliva may be too short to obtain a valid assessment. Nevertheless, patients experienced dry mouth and an altered salivary viscosity, which may confirm that most patients were suffering from the reduced salivary secretion rate.

Patients receiving chemotherapy did not experience frequent oral symptoms, although some of them reported severe symptoms. Unfortunately, there is no reliable predictor of who will develop such symptoms, which emphasises the importance of referring all patients to dentistry before the start of treatment. In Study V, most patients receiving intensive chemotherapy were referred to dentistry before the start of treatment, but a large proportion was not although they had notes on oral symptoms in their records. In addition, some of the patients in Study IV were not examined by any professional staff although they reported oral symptoms. The oral mucositis scores peaked after two weeks. The same findings were reported by Zittoun et al (Zittoun et al., 1999), who demonstrated the highest proportion of patients (34%) with sores in their mouth at the nadir of blood counts. In the present study almost all chemotherapy patients showed some signs of mucositis, although the mean scores were lower than those of patients receiving radiotherapy. These patients reported also an increase of fatigue, a finding that is in agreement with earlier studies (Persson et al., 1995, Zittoun et al., 1999). In an interview study, Persson found that fatigue was the first symptom noticed by patients (Persson, 1995), and Zittoun et al reported fatigue to be elevated during the chemotherapy course compared to the end of the course (Zittoun et al., 1999). In both studies, patients also reported several oral problems. Fatigue may be one reason for unsatisfactory maintenance of oral hygiene procedures. Body weight increased unexpectedly, despite the fact that patients reported difficulties eating and taste alterations. A closer analysis demonstrated that this increase was attributable mainly to two individuals.

The gingivitis score increased during the assessment period for both groups, although oral hygiene was judged to be good or excellent throughout the study. However, the assessment of oral hygiene may have been too global. A more thorough assessment may be required for mapping the relationship between oral hygiene and gingivitis during cancer treatment. Patients reported that they had some difficulties with their oral hygiene procedures.

Oral health and health-related quality of life

The finding that oral symptoms were significantly related to HRQOL was illustrated by three different methods: patient reports in interviews, the differences in HRQOL and oral symptoms between patients who reported that oral symptoms had an influence on their HRQOL and those who did not, and the correlations between the EORTC instruments and patient experiences assessed by the VAS. These findings support the approaches to oral health-related quality of life suggested
by Gift et al (Gift and Atchison, 1995). The oral cavity was compromised for the majority of the patients (88%), and there was a relation between oral symptoms and HRQOL. However, the present study allows no conclusions about the directions of this relationship.

In all correlational analyses, independent of patient group, there were associations between oral symptoms, physical functioning and social functioning. Similar findings have also been reported by Bjordal et al (Bjordal et al., 1999). These aspects of HRQOL seem to be most affected by oral problems. The suggestions by MacEntee et al (MacEntee et al., 1997) that oral health is a mix of three themes: comfort (including pain and eating), oral hygiene (the significance of a clean mouth) and general health, are supported by the present findings. Oral pain and problems with social eating increased during treatment among patients receiving radiotherapy and the latter problem remained elevated one month after treatment. Patients who reported that oral symptoms had an influence on their HRQOL reported higher scores for pain and social eating, even though the latter did not reach statistical significance. A main proportion of all patients (61%) reported difficulties to eat. For patients receiving chemotherapy, there was a relation between the feeling of a clean mouth and all functional scales but role functioning, which supports the significance of a clean mouth for HRQOL. In addition, there were significant correlations between communication problems and both role and social functioning for patients receiving radiotherapy. The pattern of results on the oral symptom VAS corresponded to those of the EORTC questionnaires which confirms the notion that oral health and general health are two sides of the same coin.

The findings from the EORTC QLQ-H&N35 instrument are in agreement with those reported by Hammerlid et al, who found that symptoms increased until 2 or 3 months after the start of treatment, although dry mouth and taste alteration remained until the 1-year follow-up (Hammerlid et al., 1997b). Bjordal et al found that the EORTC QLQ-H&N35 questionnaire is sensitive to change over time within groups and reported an increase in multi-item and single items similar to that in the present study (Bjordal et al., 1999).

Within dentistry, health and oral health is very often defined as the absence of disease. However, health is a dimension separate from disease. It incorporates psychosocial and social functioning in addition to physical functioning. Besides, the influence on everyday life is an important part of health. There is no previous study in which patients were interviewed regarding their experiences of oral symptoms and their relation to HRQOL. In the present study, patients reported problems performing oral hygiene, eating and drinking and communicating with others, which is in agreement with earlier findings (Bjordal et al., 1995, Epstein et al., 1999, Hammerlid et al., 1997a). They did not feel that their mouth was clean, which may have reduced their self-esteem (MacEntee et al., 1997). In addition, they reported that their oral symptoms had an influence on their quality of life. These results attest to the notion that oral health is strongly related to HRQOL.
HRQOL did not change appreciably among patients receiving chemotherapy, neither did the experience of oral symptoms. This is in agreement with Zittoun et al who found no significant changes over time of the average overall physical condition, quality-of-life, physical functioning or social functioning scores. However, there were increases of mouth sores, mouth dryness and difficulty swallowing at the nadir of the blood counts, but no change in taste and dental problems (Zittoun et al., 1999). Persson et al found reduced quality of life scores among patients with leukaemia and highly malignant lymphoma over a period of two years, with the most pronounced reduction in relapsing patients. Patients also reported dry mouth, swollen tongue, pain, blisters, gingivitis, dental problems and altered taste (Persson, 1998). However, relations between oral symptoms and HRQOL were not investigated in any of the studies. The fact that most of the functional quality-of-life scales were significantly related to the summary score of oral symptoms in the present study, supports the notion that oral health plays an important role in health perception.

In the present study, HRQOL was assessed by the EORTC QLQ-C30 and the EORTC QLQ-H&N35 questionnaires. They are both well-known instruments that have been validated in a number of studies, and they are sensitive to changes (Aaronson et al., 1993, Bjordal et al., 1999, Bjordal and Kaasa, 1992, Bush et al., 1995, Epstein et al., 1999, Hammerlid et al., 1999, Osoba et al., 1998, Persson et al., 1995, Zittoun et al., 1999), which supports the reliability of the HRQOL results of the present study.

**Education, knowledge and attitudes to oral care**

The most important knowledge for hospital staff is to recognise healthy signs and symptoms of disease in the oral cavity, and to understand when dental staff should be contacted for further examination. In the present study, nursing staff rated their knowledge on oral signs and symptoms and examination of the oral cavity to be the poorest, nurses even poorer than enrolled nurses. To be able to detect symptoms of disease, it is necessary with regular examination, if possible daily. The fact that nurses who performed daily examination felt more comfortable to discuss oral hygiene and did not object to examining the oral cavity illustrates the importance of regular examination. The continuous improvement in dental status among individuals in Sweden (Österberg et al., 1995) emphasises the importance of improved knowledge. Knowledge on cleaning dentures, which will likely be needed less often in the future, was rated high by nursing staff. It appears necessary to improve the education in oral health science for nursing staff and in addition, to improve and promote continuing education in oral care. This was reflected in nursing staff statements in the present study. This should be done in close co-operation with dental staff. Dental hygienists keep abreast with the research within oral health science, but this must be shared with nursing staff in an ongoing continuing education system. Such an arrangement has been shown to be efficient by
An interesting and important finding was the discrepancy between nursing staff and patients regarding their attitudes to oral examination and oral hygiene. It is obvious that many nurses have too cautious an attitude to oral examination and procedures involved in oral care. Patients apparently do not experience any discomfort at the prospect of an oral examination. Neither do they consider talking about their oral health status to be any different from speaking about health in general. One reason why nurses objected to examining the oral cavity is probably lack of knowledge and experience.

**Oral care and self-care**

In the present study, a carefully prepared oral care program for patients receiving radiotherapy was used on the wards studied. All patients were referred to dentistry before the start of treatment and were examined regularly. However, these patients are also in the need of regular maintenance after treatment termination due to the persisting side effects of radiotherapy. Dental staff has to be aware of remaining side effects and maintain patients properly on a regular basis.

Many patients receiving chemotherapy were not referred to dentistry despite distinct recommendations (Jontell and Koch, 1995, National Institute of Health Consensus Development Conference, 1989). This may be due to a lack of knowledge on the part of staff. The fact that many patients were outpatients with lymphomas who were not expected to receive the most intensive chemotherapy may have had an impact here. Although some of them did not experience any oral symptoms, some did so without being in contact with dental staff to discuss their problems. The co-operation between dental and hospital staff with regard to how to care for patients receiving chemotherapy seems to be deficient. It is important to improve the routines for oral care including regular oral assessment. The introduction of nursing staff to an assessment guide that is simple and useful could facilitate assessment as stated by staff in Study III.

Several patients reported eating problems, sometimes due to taste alteration and loss of appetite. This may not be considered an oral problem, but the presence of saliva is important for taste sensations (Ekström, 2000). Even if the salivary secretion rate did not change for all patients, some of them experienced mouth dryness. They may have benefited from advice on saliva substitutes to improve their taste. Lip dryness was another symptom that was reported to bother some of the patients, but none had been informed on lip care products.

Oral hygiene was assessed by a global score, which limits the conclusion regarding the influence of plaque. A more thorough assessment is desirable in future research, particularly since many patients reported difficulties with their oral hygiene and a feeling that they did not have a clean mouth, even though they performed oral hygiene frequently. Those patients who had been
instructed in oral hygiene brushed their teeth more often than those who had not. In view of this finding, it would have been interesting to see if this was reflected in a thorough oral hygiene index assessment. People need to know how, not only why, to comply with extensive oral hygiene procedures (Rich, 1995). In addition, written information, which was shown to be uncommon in the present study could be an important resource for patients. Patients brushed their teeth more often than they used toothpaste, a coincidence that may depend on the taste and composition of the toothpaste. Mild toothpastes including fluorides are available that would be more easily tolerated by patients with an affected oral mucosa, a fact that patients need to be informed about.

**Documentation of oral status and oral care**

There are serious flaws in the contemporary documentation of oral care. Similar results have been reported by Ehrenberg et al who found a very poor agreement between patients’ statements and data from records on several aspects of nursing care, but specifically on oral conditions (Ehrenberg and Ehnfors, 2001). Although no explicit comparisons with patient status were made, in the present study the discrepancy between physicians’ and nurses’ documentation was so large that more oral problems than were found in the nursing records are likely to have existed. If and how examination has been performed and what care has been provided and evaluated is not always reflected in the documentation. In the present study, almost all patients reported some symptom, which should have been noted in their records. However, the records of patients who were interviewed were not scrutinised. This means that conclusions from Study V were based on a review of records and not on observations of patients. However, notes in patient records may be an indicator of the care provided. Deficiencies in records may cause serious errors in care because important information is lost (Ehrenberg, 2000). If the patients’ problems are not detected, there is no possibility to provide adequate care. To meet patients’ needs during treatment, their oral status, care plans and nursing procedures have to be carefully documented. Standardised instruments for the assessment of oral status and sufficient staff knowledge and skills are important.

**Methodological considerations**

The patient samples (Studies I, II and IV) are relatively small, which limits the conclusions of the present study. It should be noted that several earlier studies on this group of patients also employ small samples (Bernhoft and Skaug, 1985, Langius, 1995, Persson et al., 1995, Wahlin and Matsson, 1988). However, the present patients were included consecutively and the oral symptom pattern among patients receiving radiotherapy are in agreement with results of previous research (Bjordal et al., 1999, Epstein et al., 1999, Hammerlid et al., 1997a), with an increase of oral discomfort from the start until the end of treatment and symptoms remaining after treatment termination.
The studies are limited to two hospitals in Sweden, although one is a university hospital and one a regional hospital, which should improve the external validity of the findings. There was a low non-participation rate in all studies.

Most of the instruments (OMI, salivary secretion rate, DFS, HRQOL) are well-known methods with proven validity which attests to the confidence that can be placed on the conclusions. The oral mucositis index according to Schubert et al was used (Schubert et al., 1992). In the present study, it was of interest to assess mucositis carefully because even very local and small lesions may cause discomfort and be noticed by patients. The inter-rater agreement calculated as percentage agreement (0.91) and Cohen’s kappa (0.64) was sufficient (Study I). Resting saliva was collected only for 5 minutes, which may be too short to yield a valid measure in patients with hyposalivation. To provide a valid DFS index, there is a need for a more thorough examination including x-rays, which was not possible in the present study, because dental staff had not examined all patients. However, the DFS index was used here only to give an indication of patients’ dental status and was not used for the analyses.

The VAS used to assess patient experiences was a revised version of that presented by Kosac et al (Kosac et al., 1996). The findings from this scale are in agreement with those of the EORTC QLQ-H&N35, a validated instrument (Bjordal et al., 1999), which enhances the validity of the conclusions on patients experiences.

In the interviews with staff, the categorisation of statements was made by the author, which may give rise to questions of bias. However, since a majority of the questions concerned “matter of fact” issues, no advanced interpretation was necessary. Inter-rater agreement was assessed for the analyses of the patient interviews. The author categorised the statements and a second assessor sorted them using the predetermined categories. These procedures should be sufficient for the conclusions of the present study, but the fact that the interviewer was a dental hygienist may have influenced the replies of the nursing staff in a socially desirable direction.

It would have been of interest to use a more thorough oral hygiene index. This would have improved the data on the frequency of performance of oral hygiene procedures. The daily self-recording form was simple, but some patients may have been too weak to complete it accurately.

The five studies approach the field of oral health and oral care from different perspectives. They were performed during different periods in partly different settings, which limits the comparisons of results between studies. This is most apparent concerning possibilities for direct comparisons between interviews with staff and patients. These two studies were performed approximately one year apart.

The fact that all types of oral symptoms increased for patients receiving radiotherapy irrespective of regular oral care by dental staff, indicate that oral symptoms are difficult to treat. The
present study allows no conclusions about how these patients would have experienced their oral discomfort without the support received, because no control group was included.

A positive feature of the present study is that the relation between oral health and HRQOL was assessed by three methods: patient reports in interviews, the differences in HRQOL and oral symptoms between patients who reported that oral symptoms had an influence on their HRQOL and those who did not, and the correlation between the EORTC instruments and patient experiences assessed by the VAS. This strongly supports the conclusion that oral health is related to HRQOL, which emphasises in the importance of a multi-disciplinary approach to oral care.

**Implications for future research**

In order to provide evidence-based oral care and nursing, it is essential to achieve scientific evidence concerning the effects of oral programs for patients receiving cancer treatment. Existing protocols are employed in clinical practice to a varying extent and there is a lack of research within this field (Barker, 1999, Lunn, 1998). In order to avoid the small sample sizes commonly used, it would be desirable to perform multi-centre studies. Of particular interest would be to investigate if instruction in oral hygiene has any impact on patients’ self-care compliance and routines. In addition, it is essential to study the influence of regular standard plaque removal on oral symptoms. Extended routines for referral to dentistry, including all patients receiving chemotherapy need to be evaluated with a focus on the frequency of oral symptoms.

A challenge would be to include more oral care in the basic education of nursing staff and to provide a continuing education program repeatedly, and to evaluate if such education has any impact on attitudes and if it is beneficial for patients. Further studies are also warranted of the frequency of oral symptoms among patients receiving chemotherapy and what impact such symptoms have on patients’ health-related quality of life.

In addition, it would be of interest to investigate if an extended use of key words in nursing diagnosis and a more thorough documentation could facilitate the co-operation between nurses and dental hygienists and if that has any consequences for patients.
CONCLUSION

The major conclusions of the present study are as follows:

♦ Patients receiving radiotherapy experienced an increase of oral symptoms irrespective of the oral care provided. These symptoms remained to a large extent one month after treatment.
♦ Overall, patients receiving chemotherapy experienced fewer and slighter oral symptoms than did patients receiving radiotherapy.
♦ There was good correspondence between symptoms perceived by patients and complications assessed by dental staff.
♦ Oral symptoms were significantly related to patients’ health-related quality of life, particularly among those receiving radiotherapy.
♦ There is a lack of adequate education and continuing education in oral care among nursing staff.
♦ The attitudes to oral examination and discussion on oral hygiene differed between nursing staff and patients. Nursing staff objected to examining the oral cavity referring to patient integrity. This was not considered as a hindrance among patients.
♦ Referrals to dentistry before the start of medical treatment were not performed sufficiently often among patients receiving chemotherapy.
♦ Daily examination was rare. All patients receiving chemotherapy were not examined orally before or during treatment.
♦ Information on oral complications and oral hygiene were insufficient.
♦ Patient compliance with oral hygiene procedures was acceptable. However, some patients reported difficulties. Patients who received instructions on oral hygiene performed oral hygiene procedures more frequently than those who received no instruction.
♦ Oral status and oral care was insufficient documented, particularly in nursing records.
ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to:

♦ Professor Per-Olov Sjödén, my primary supervisor and co-writer, for excellent guidance, inspiration, support and constructive criticism.

♦ Odont. Dr. Ylva-britt Wahlin, my second supervisor and co-writer, for encouragement, support, constructive criticism, friendship and magnificent humour.

♦ Professor Anders Wahlin, my co-writer, for support, encouragement and constructive criticism.

♦ Doctoral Student Marie Elf, my co-writer, for inspiration, encouragement and friendship.

Special thanks to

♦ The patients for their kind participation in the study.

♦ The nurses and enrolled nurses for their kind participation in the study, and specifically the nurses who were contact person on each ward for their co-operation and enthusiasm to participate in including patients.

♦ Katarina Gahnberg for supporting me in gathering data and for encouragement and friendship.

♦ The staff at the Department of Oral and Maxillofacial Surgery – Hospital Dentistry, Akademiska Hospital, Uppsala for all kind of support with the collection of data.

♦ Solveig Hannersjö, for providing me with generous working conditions, and for never-ending encouragement, support and friendship.

♦ Solveig Sundin and the library staff for encouragement, support and outstanding service.

♦ Ylva Rohlén for supporting me with all kind of practical issues.

♦ Marianne Omne-Pontén for being my mentor during the initial phase of the study.

♦ Anna Ehrenberg for encouraging support in completion of this thesis.

♦ Britta Pettersson, Lars Jacobsson and Gram Svärdström och for being my first teachers and inspirers within the field of Dental Hygiene.

♦ Anders Ström for encouragement and assistance with the scientific presentation.

♦ Eva Kvarnström for valuable advice on lay-out.

♦ Maj-Britt Sundelin and the staff at the Department of Public Health and Caring Sciences Uppsala University for assistance with practical matters.
♦ All colleagues at the Section of Caring Sciences, Department of Public Health and Caring Sciences Uppsala University for interesting interdisciplinary discussions and constructive criticism in courses and seminars.
♦ All colleagues at the Section for Dental Hygiene at Högskolan Dalarna and especially Gun Sandberg my co-worker as teacher and student over the years for encouragement, support and inspiring discussions.
♦ All colleagues at the Department of Health and Caring Sciences at Högskolan Dalarna for inspiring environment and fruitful discussions.
♦ My employer Högskolan Dalarna for providing me with generous working conditions
♦ All personal friends and colleagues for being there, when I needed you.

Lastly
♦ Staffan, my dearest husband and my greatest love who always have supported me in life as well as my professional career
♦ Leonard our son and my greatest joy in life
♦ My dear sister Barbro and her family Lars, Håkan, Anna, Malin, Johan, Viktor, August, Peter, Ann-Sofie, Samuel and Tobias for being my extended family through all phases of my life.

The studies were supported by grants from Dalarna Research Institute, The former Falun College of Health and Caring Sciences (Vårdhögskolan), the Department of Public Health and Caring Sciences, Section of Caring Sciences, Uppsala University, Högskolan Dalarna – Health and Caring Sciences and The Swedish Dental Society.

The Department of Public Health and Caring Sciences, Section of Caring Sciences, Uppsala University and Högskolan Dalarna – Health and Caring Sciences generously supported the printings of this thesis.
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