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**ASPECTS OF NURSING CARE
FOR PATIENTS WITH HEAD AND NECK
CANCER RECEIVING RADIATION
THERAPY**

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Stockholm 2006

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Published and printed by Repro Print AB, Stockholm, Sweden, 2006

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ISBN 91-7140-619-0

ABSTRACT

Head & Neck (H&N) cancer accounts for approximately 3 % of all cancer in Sweden. The treatment options include radiotherapy (RT), surgery and/or chemotherapy. Both the disease and the treatment cause side effects that often have great impact on the patients. Many H&N cancer patients have limited social networks and have been found to have a worse general health (both physically and mentally) compared with the general population. A majority of these patients are smokers and many also have other types of substance abuse.

The general aim of this thesis was to improve the nursing care for H&N cancer patients undergoing RT. The four studies included, predominantly focus on information and communication (paper I), immobilization and reproducibility during RT for H&N cancer (paper II) and smoking cessation (paper III and IV).

In paper I, the helpfulness of a care diary, aiming to improve information and communication, was evaluated through anonymous questionnaires from H&N cancer patients, family members and clinicians. The results indicate that the overall impression of the care diaries were good or very good among 85 % (n = 99) of the responders. The evaluation gave information on the usefulness of the diaries, suggestions for improvements in layout and content and also indicated difficulties, such as lack of involvement among clinicians, time-consuming and lack of information about the care diaries among some clinicians.

In paper II, two types of thermoplastic face masks (Posicast®) for immobilization during RT were compared, regarding reproducibility of patient position over time, radiation skin reactions and the patients' subjective experiences of using the masks. In this trial, 260 patients were randomised to one of the two types of face mask. One hundred and forty one patients were evaluated. We found no difference in reproducibility, pain, fit, discomfort or possibility to move the head within the mask during RT between the two types of masks. However, patients using the longer head and shoulder mask (HSM) experienced significantly more claustrophobia ($p = 0.023$). Patients allocated to HSM and receiving ≥ 60 Gy were also found to have more radiation skin reaction, according to the WHO scale for acute or sub acute toxicity.

In paper III, H&N cancer patients and nurses experience of a nurse-led smoking cessation program was explored. In this qualitative study, data was collected from diary notes (kept by six patients and two nurses) concerning 13 H&N cancer patients, focusing on the smoking cessation process. Data was analysed using the Framework approach. The most important finding was the therapeutic value of the patient-nurse relationship, described by both patients and nurses. The results were presented in three major categories; patient-nurse relationship, factors facilitating and hindering behaviour change and drug (ab)use.

In paper IV, the effectiveness (proportion of smoke-free patients) of the nurse-led smoking cessation program for 50 H&N cancer patients planned for curative RT was evaluated, with one-year follow-up. Thirty-seven (74 %) of the patients were tested (measuring carbon monoxide in expired air) smoke free weekly during RT, and of the 41 patients alive after one year 28 (68 %) were reported and tested smoke free at the one-year follow-up.

Care diaries seem to be a useful tool in communication between H&N cancer patients, their families and clinicians. We recommended that the care diaries should

be implemented in the standard care for H&N cancer patients after improvements but a more sophisticated evaluation on a larger sample is needed.

When choosing an immobilization device for H&N cancer patients undergoing RT, a more individual approach is recommended and the shorter head mask (HM) is suggested as first choice, to reduce the risk severe skin toxicity, especially for patients receiving ≥ 60 Gy and/or with previous experiences of claustrophobia.

Smoking cessation could successfully be implemented into standard cancer care and even H&N cancer patients with a heavy nicotine addiction and multi drug abuse could successfully quit smoking with systematic support from the multidisciplinary team. However, to more accurately evaluate the effect of this nurse-led intervention program, further studies are on going, involving larger groups of patients and suitable control groups.

Key words: Head and neck cancer, radiotherapy, nursing, smoking cessation, care diaries, immobilization, reproducibility.

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- III. Sharp L., Tishelman C.
Smoking Cessation for Patients with H&N Cancer- A Qualitative Study of
Patients' and Nurses Experiences in a Nurse-led Intervention.
Cancer Nursing 2005; 28 (3): 226-235.
- IV. Sharp, L., Lewin, F., Johansson, H., Fagerström, K.O., Rutqvist L.E.
Smoking Cessation among Patients with Head & Neck Cancer - Cancer as a
"Teachable moment".
Submitted.

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LIST OF ABBREVIATIONS

RT	Radiotherapy
Gy	Gray
H&N	Head and Neck
CT	Computer tomography
MRI	Magnetic resonance imaging
COPD	Chronic obstructive pulmonary disease
IMRT	Intensity modulated radiotherapy
CO	Carbon monoxide
PPM	Parts per million
FTND	Fagerström Test for Nicotine Dependence
ENT	Ear, Nose and Throat
CI	Confidence interval
HM	Head mask
HSM	Head and shoulder mask
GPs	General practitioners
FNAC	Fine needle aspiration cytology
EORTC	European Organization for Research and Treatment of Cancer
RTOG	Radiation Therapy Oncology Group
WHO	World Health Organization
NCI	National Cancer Institute
RISRAS	Radiation Induced Skin Reaction Assessment Scale
NRT	Nicotine replacement therapy
ANP	Alternative nicotine products
UICC	International Union Against Cancer

PREFACE

The issues and research questions dealt with in this thesis has been developed during my practice as a clinical nurse at Radiotherapy (RT) unit at the Karolinska University Hospital, Huddinge (former Huddinge University Hospital) in Stockholm, Sweden. I have worked at this department since 1985. During the years I have developed a special interest for clinical nursing issues related to radiotherapy. My clinical impression is that patients with head and neck (H&N) cancer are especially vulnerable and in need of extra attention and nursing care during their pre-, treatment and post-treatment phase. Since 1996 I have worked more or less exclusively with H&N cancer patients and their families. I have developed and implemented a nurse-led outpatient clinic. Parallel to the research and clinical work, I have also been involved in different projects to improve and develop quality of care for this group.

I have a clear awareness that many of the issues studied in this thesis, such as smoking cessation, fixation techniques and communication and information with patients, are multidisciplinary issues. In this thesis I have approached these issues from my own nursing perspective. I am also fully aware that the typical risk factors for H&N cancer discussed in this thesis are not relevant for all patents with H&N cancer.

Since my focus has been H&N cancer patients undergoing RT, other treatment options, even if not less important, are only described briefly.

The four studies in this thesis are all based on the department where I work. Conditions, care systems, routines and organisation discussed are therefore mainly influenced from this environment. I am fully aware of the great variations in how RT units are organised and how RT nurses work, both between different countries but also to a great extent between RT units in Sweden.

1 INTRODUCTION

1.1 HEAD & NECK CANCER

Head and Neck (H&N) cancer accounts for 3 % of all cancers in Sweden. The incidence has been relatively stable since the 1970s [1]. The term H&N cancer includes several malignant tumours in the head-neck area. The tumours occur at the following sites: lip, tongue, floor of mouth, gum, other oral cavity sites, salivary glands, oropharynx, hypopharynx, nasopharynx, larynx, nose, sinuses, ear and thyroid. Sometimes the term also includes skin cancers (such as squamous cell carcinomas or malignant melanomas) in the H&N area and neck metastases with unknown primary cancer. The most common type of cancer (90 %) in the H&N area is squamous cell carcinoma [2]. Another type of cancer, adenocarcinoma, arises from the glandular tissues in the salivary and thyroid gland. Other less frequent types of tumours are; acinic cell carcinoma, mucoepidermoid carcinoma, adenoid cystic carcinoma, lymphoma, sarcoma and pleomorphic adenoma.

The TNM staging system, developed and maintained by the International Union Against Cancer (UICC), a global standard for categorising cancer, is used in the treatment decision process, predicts prognosis and it enables treatment comparisons between different centres. T refers to the primary tumour and range from T0-T4. N refers to nodes (regional lymph node involvement) and range from N0-N3. M refers to distant metastases and range from M0 (no distal metastasis) to M1 (distant metastasis). The letter X is used after T, N or M when status cannot be assessed. The prognosis of H&N cancers varies to a great extent and is depending on tumour site and stage.

The symptoms of H&N cancer are often similar to symptoms that occur in much less serious conditions. These symptoms include hoarse voice, sore throat and dysphagia¹, ulcers in the oral cavity, earache and swollen lymph glands in the neck. Most patients seek help from their general practitioners (GPs) [3] who might see hundreds of patients with similar symptoms without H&N cancer, so cancer diagnosis in early stages might be difficult. Follow-up is therefore of great importance, especially for patients exposed to specific risk factors, such as smoking and alcohol and/or persistent symptoms. Follow-up involves instant referral to site-specialist cancer treatment teams for further diagnostic procedures. The time aspect is of great importance, since large tumours are generally more difficult to treat than small tumours, and the diagnostic procedure could also be time consuming.

Some studies suggest that H&N cancer patients are likely to neglect their symptoms or to have low levels of awareness which might delay diagnosis [4]. My clinical experience is that people in general are less familiar with H&N cancer, compared with more common types of cancer, such as breast, prostate or lung cancer.

H&N cancer is more common among men (70 %) and a majority of the patients are older than 60 years [1]. Research has found that H&N cancer patients more often live alone and come from deprived areas [5, 6]. Smoking and drinking may have a deep

¹ Difficulties in swallowing

social meaning and may be used to reduce stress and has therefore become an important part of their lifestyle.

The general health among patients with H&N cancer has been found to be worse than among other groups of cancer patients [7]. Feber found [8] in a study on 188 H&N cancer patients that 81 % of the patients did not work prior to treatment. Of these, 73 % patients were retired and as many as 20 % were on long sick leave. The same study also showed that 54 % of the patients suffered from other medical conditions, such as lung or heart disease. In another study (n = 570) by Terrell et al. [9], 31 % of the patients reported one co-morbid medical condition and 37 % reported two or more co-morbid conditions at time for H&N cancer diagnosis. The same study also found that co-morbidity was strongly related to poor quality of life. Both Duffy et al. [5] and Terrell et al. [9] showed that 44 % of patients with H&N cancer had depressive symptoms. In my experience, the social isolation and depression that many H&N cancer patients live with, often leads to negative experiences with authorities. This might result in reluctances to seek medical help and a first presentation to the health care system with advanced tumours is not uncommon [3, 9, 10].

Even if these circumstances are typical for patients with H&N cancer, there are plenty of exceptions and some patients have none of the above-described characteristics.

1.1.1 Risk factors

Smoking and high alcohol consumption have been found as the primary and most influential risk factors for H&N cancer [11]. These risk factors are relevant for the squamous cell carcinomas in the H&N area. Cancers in salivary or thyroid glands, nose and sinuses have been described to have a different pathology and their etiology has been found to be more uncertain [12].

Cigarette smoke contains several carcinogenic agents and research has shown that 85-90 % of patients with H&N cancers are active or previous cigarette or pipe smokers [13, 14]. High alcohol consumption has also been shown to increase the risk for H&N cancer, especially in combination with smoking [11]. Some types of oral snuff used in other parts of the world, especially Asia, are also known to cause H&N cancers, mainly in the oral cavity [15].

There is also evidence that occupational exposures to high levels of wood dust or chemicals can cause some types of H&N cancers [12]. A diet with a low intake of fruit and vegetables [16] may also increase the risk for oral cancers.

1.2 DIAGNOSTIC PROCEDURE

As described, the symptoms of H&N cancer may be easy to miss at an early stage of the disease. Studies have shown [3] that some patients do not even note any symptoms and the tumour is found when the patient seeks medical or dental help for other conditions. Dentists need to be observant if patients have persistent oral ulcers but my clinical experience is that many people in this population do not visit dentists regularly if at all. Even if GPs and dentists have been found to be [3, 10] the most common first care provider, nurses, dental hygienists and other groups of clinicians² also need to be

² Health care professionals, such as nurses, oncologists, dieticians or psychologists involved in clinical practice.

alert of symptoms of H&N cancer and a referral to an Ear-, Nose-, and Throat (ENT) department should be initiated as soon as possible if a suspected lesion in the H&N region is found [3]. The diagnostic procedure typically includes a physical examination (palpation and inspection) followed by an endoscopic examination under general anaesthesia including biopsies. The diagnostic procedure may also include Computer tomography (CT), Magnetic resonance imaging (MRI) and ultrasound scanning of the neck, possibly including fine needle aspiration cytology (FNAC) [3]. All elements in the diagnostic procedure need to be [17, 18] carefully planned and coordinated to avoid delays in diagnosis. There might be waiting time for some of these procedures and well-established [3] routines in collaboration with X-ray and pathology departments are therefore essential. When all diagnostic information is available, the patient is usually discussed at a multidisciplinary conference, which includes physicians, nurses and other health care providers, who are specialists in different fields, such as oncology, ENT, pathology, nutrition etc [19]. This is typically the moment when the diagnosis and treatment options are discussed with the patient and it is therefore essential that patients are well prepared. Family members³, if available, are encouraged to participate. The pre-visit information should include information on the purpose, participants and procedure of the conference. The diagnostic period for some H&N cancer patients has been described as a period filled with high levels of uncertainty and distress [20] and during this period patients may experience a possible cancer diagnosis as an unknown threat. My clinical experience is that some H&N cancer patients may even be relieved when the diagnosis is actually mentioned to them, even if a large variety of reactions are to be expected.

1.3 TREATMENT OPTIONS

The treatment options for H&N cancer patients are radiotherapy (RT), surgery and chemotherapy [8]. In general, less advanced cancers might be treated with single modality treatment (surgery or RT), whereas more advanced cancers might be treated with a combined treatment regime. When surgery is not possible or desirable, RT is normally suggested as single modality treatment. There are different traditions in what order the treatments are delivered. In Sweden, RT followed by surgery is the most common sequence for patients with H&N cancer.

The patients' general health also determines to the treatment options. In some cases, surgery might not be possible due to other medical conditions, such as chronic obstructive pulmonary disease (COPD) or heart disease. My experience is that in some cases, RT might not be possible due to claustrophobia, psychiatric disease, or orthopaedic conditions, which makes it impossible for the patients to lay flat on the RT couch. Chemotherapy may be contraindicated, in instance for patients suffering from kidney or liver conditions. Curative treatment aims to eliminate the primary cancer and any neck nodal metastases. Palliative treatment is offered if cure is not a realistic goal. The aim is then to reduce symptoms. My clinical experience is that the treatment outcome may often be difficult to predict. There may be long-term survivors among patients treated with palliative RT, and patients with early progressive disease among those treated with RT with a curative intent.

³ Both immediate family members, relatives or any other person that the patient has a close contact with are, for practical reasons, included in this definition in this thesis.

1.4 RADIOTHERAPY

Patients with H&N cancer do not account for a large proportion of the patients on RT units, in Sweden and many other countries with a low incidence of H&N cancer [1]. However, each H&N cancer patient's treatment is complex and resource consuming, compared to most other types of RT treatments. RT for H&N cancer patients has also been found [21] to have a greater impact on the patients' health compared with most other groups of cancer patients receiving RT, due to severe side effects.

1.4.1 Radiotherapy techniques

The standard RT technique, in Sweden and many other countries, has for many years been external beam, fractionated RT, with one fraction per day, five days a week during five to seven weeks. However, newer techniques, such as accelerated and hyper fractionated RT [22] or concomitant radio-chemotherapy [23] are nowadays more common and have been found to improve outcome but also to increase the risks for severe acute side effects. Other new RT techniques, such as intensely modulated RT (IMRT) and conformal RT, with the aim of optimizing the dose to the tumour and reducing the doses to normal surrounding tissues and thereby reducing side effects, are also more common today. Another technique to deliver RT to H&N tumors is brachytherapy, where a radioactive source is placed in or close to the tumour. The dose delivered remains more localized, protecting surrounding tissues. Brachytherapy is used on its own, for example to treat smaller lesions [8]. It can also be combined with external RT [24].

The dose planning prior RT for patients with H&N cancer is complex due to the locations of the tumors. Closely located organs, such as brain, spinal cord and eyes, need to be shielded from the beams as much as possible. Some organs might not be possible to avoid, but the 3-D dose planning⁴ aims to keep the delivered doses to organs like salivary glands or skin as low as possible.

1.4.2 Positioning and fixation

The daily positioning of the patient is crucial for an accurate and consistent RT treatment. The positioning needs to be repeated as exactly as possible, to ensure that the aimed target volume is being treated every day, and also to avoid day-to-day set-up errors. It is often necessary to use an immobilization device to prevent movements during treatment. A commonly used immobilization system is thermoplastic face masks. There are many types of such masks available, which have been found to result in a more accurate reproduction of the treatment position [25-27]. However, the thermoplastic face masks have also been found to increase the risk for acute skin reactions [28-30]. My clinical impression is that many patients experience claustrophobia, due to the face masks but I found no published data on patient comfort and/or tolerability with thermoplastic masks. Prior to our study (paper II), two types of Posicast[®] thermoplastic masks were used at our department. No evaluation had been performed and the clinicians within the multidisciplinary team, had different opinion on which of the two masks should be used. A typical opinion

⁴ A computer based process that allows the RT staff to model, predict, and optimize the total dose of radiation to target or tumor volumes and minimize dose to critical normal surrounding tissues, before delivery of the prescribed RT.

among the RT nurses was that the longer, head and shoulder mask (HSM) resulted in better treatment reproducibility and was therefore considered the better alternative. A common opinion among the oncologists was that the shorter head mask (HM) was the better alternative, since the HSM may affect the contrast of the image in the port films⁵ and thereby make clinical evaluation more difficult.

1.4.3 The pre- treatment phase

The pre-treatment phase is here defined as the period from referral to the RT-unit to the start of treatment. It often includes a series of new and unfamiliar procedures for the patient in an extremely high-tech environment. According to Burnet et al. [31], this period should be as short as possible to avoid treatment delays that might worsen the outcome but also need to be long enough to allow for dental care, the making of the immobilization device, RT planning CT, 3-D treatment dose planning and pre-treatment simulation (Figure 1). The pre-treatment period also needs to allow time for treatment calculations by physicists. Jensen et al. [32] showed in a small study (33 H&N cancer patients) that a delayed RT start (approx. 4 weeks) led to a significantly increased tumour size for the majority of the patients and an increased risk of lymph node metastasis.

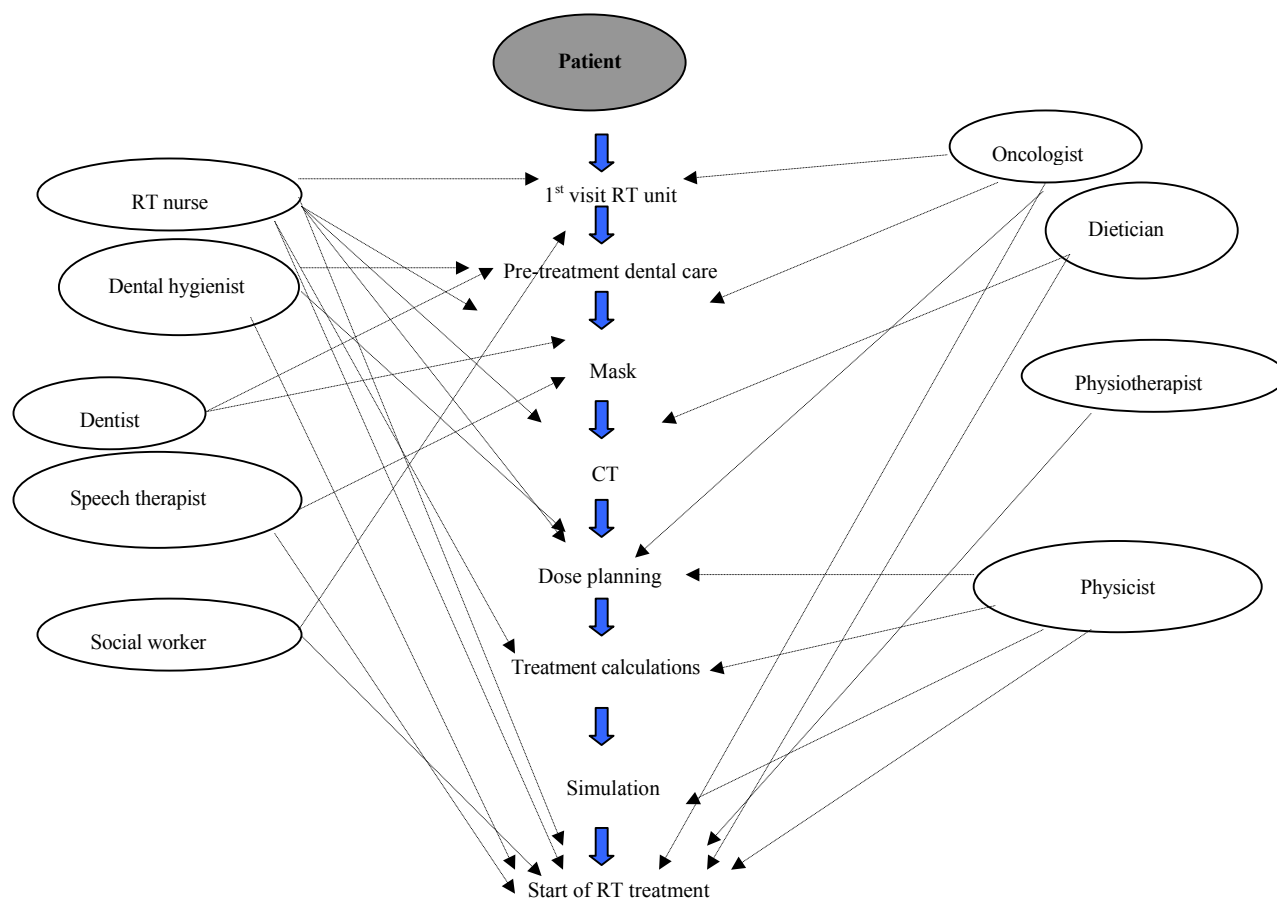
Sherman et al. [33] found that many H&N cancer patients find it extremely worrying during this period to know that the cancer might grow and that the treatment cannot be initiated for weeks. My experience is that many RT units have a heavy workload and/or shortage of staff. Waiting time for treatment is therefore not uncommon. H&N cancer patients need to be prioritized, especially if RT is the first treatment, since a delayed treatment involves an increased risk for treatment failure. Even if no waiting time exists, the length of time required to complete RT treatment planning is usually several days.

The RT nurses typically coordinate the pre-treatment period (Figure 1). During this period a RT nurse case manager also initiate contacts with other clinicians, such as speech therapists, dieticians, dentists, dental hygienist, social workers and physiotherapists. As mentioned, the coordination during this period is important, to avoid further treatment delays. For instance, dental assessment and dental treatment are normally performed before the moulding of the facemask (Figure 1). Sometimes several teeth have to be removed, which might change the contour of the face and affect the fit of the mask. According to Notari et al. [34] any teeth with poor prognosis should be removed before treatment to avoid osteoradionecrosis⁶ of the mandible or maxilla. The pre-treatment period has been found to be [20] overwhelming for some newly diagnosed H&N cancer patient, who might be living an isolated life with few social contacts. The need of structure is therefore great. The typical issues associated to the pre-treatment period is further dealt with later in the section; *Nursing Care*.

⁵ X-ray image of a treatment field taken during RT, using the treating beams to expose the film.

⁶ Necrosis of bone, causes by RT.

Figure 1. The process of the pre RT period, showing an example of which professions may be involved at different stages in a Swedish RT unit.



1.4.4 Side effects

Both RT and H&N cancer may affect important functions such as respiration, communication and nutrition [8]. The biological effects on surrounding tissue, the side effects (also called early or late toxicity), have always been a source of concern in RT. The side effects from RT for patients with H&N cancer are related to the tissues within the irradiated area and they mainly include mucosal and skin reactions. The intensity of these side effects have been found to vary from patient to patient due to delivered RT dose, RT technique, treated volume, smoking habits, body mass index etc [35, 36]. Duncan et al. [37] found oral pain, dysphagia, oral mucositis, xerostomia⁷, trismus⁸, fungal or bacterial infections, oral blisters or bleedings as common side effects of RT. Eilers [38] describes oral mucositis as an inflammatory process of the oral mucosa, which may even be life threatening in some cases, since it may be portal for serious infections.

Wells et al. [35] describes the typical radiation skin reactions to involve erythema in different degree and intensity, in some cases followed by dry and/or moist desquamation⁹ in the irradiated area. Skin reactions are more likely to occur in skin

⁷ Dry mouth

⁸ Difficulty to open the mouth, due to contraction of the masseter muscle, caused by the tumour, RT or surgery.

⁹ The shedding of the outer layers of the skin.

folds, e.g. neck or behind the ears. The skin reactions may be painful and a source for infections.

Side effects normally start to appear after one to two weeks of RT and peaks towards the end or within a few weeks after completed treatment [39]. However, Öhrn et al. [40] found that some H&N cancer patients experienced oral side effects from the onset of RT. Some researchers describe an individual difference between patients, the causes which are not fully understood [41].

Duncan et al. found [37] that fatigue is a common side effect described by H&N cancer patients, both during RT and one month after completing treatment [21]. Another significant side effect of H&N cancer and/or its treatment is disfigurement. Vickery et al. [42] found that disfigurement for H&N cancer had an even greater impact on the family members. These disfigurements may be difficult to conceal, they can seriously affect self-esteem and body image and consequently lead to further social isolation [42]. Late toxicity, such as trismus, fibrosis, xerostomia, or osteoradionecrosis may occur month or even years after completing RT [8]. The management of the side effects are discussed later under the heading; *Nursing Care*.

1.4.5 Treatment interruptions

Hansen et al. argue [43] that all types of treatment interruptions during RT for H&N cancer patients should be avoided since they potentially reduce the chance of a successful treatment outcome. RT interruptions may be caused by severe side effects, technical errors, holidays and also co-morbidity [5].

1.4.6 The post treatment phase

Many H&N cancer patients have been found to be unprepared for the often intense acute side effects that typically peak at the end or during the first few weeks past RT treatment [21, 39]. For some H&N cancer patients, the past RT period is also their pre-surgery period and the patients might need to prepare themselves both physically and emotionally for the surgical procedure.

1.5 SURGICAL TREATMENT

Modern diagnostic techniques, such as MRI have during recent years improved the conditions for surgery resulting in better functional and cosmetic outcome for the patients [8]. Tumour resections including sophisticated reconstructive methods are available today. This has resulted in a reduction of the surgical morbidity [44]. Other surgical procedures that may be included in the treatment options for patients with H&N cancer are neck- dissections, where lymph nodes from the neck are removed or tracheotomy, either included in a tumour resection or to establish a free airway in a palliative situation. Some complications that may follow these procedures are wound infections, neck and shoulder pain and trismus. It is important for the multidisciplinary team to focus on nutritional intake and adequate nutritional status to reduce the risks for post-surgical infections, pressure sores and impaired wound healing [8].

1.6 CHEMOTHERAPY

Clinical trials during recent years [23, 45] have shown improved outcomes if chemotherapy is included as a treatment option for patients with H&N cancer. Concomitant RT- chemotherapy has shown promising results on survival [46]. The challenge has been to help the patients cope with the side effects, since the risk is greater for severe side effects when RT and chemotherapy is given concomitantly [47].

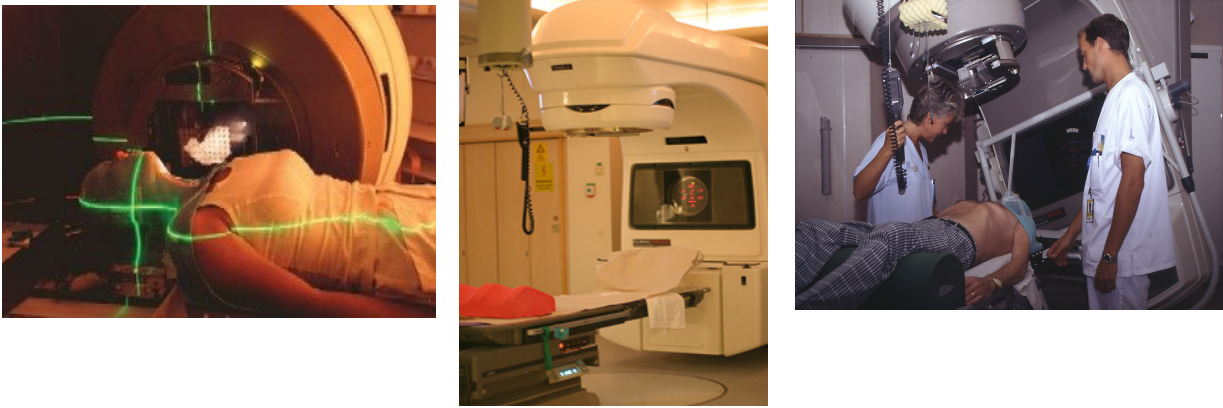
2 THE CONTEXT OF RADIOTHERAPY NURSING

2.1 THE “HIGH TECH” RADIOTHERAPY ENVIRONMENT

RT units are often located in the basement of hospitals and are constructed according to radiation safety regulations (e.g. lead shielded walls, floors and ceilings). These units are typically extremely high tech environments, which may cause anxiety and fear among patients [48] (picture 1a-c). Experienced staff is familiar with this environment and therefore may not be attentive to this possible source of worry for the patients. The environment may be strongly symbolic for some patients. Edvardsson et al. [49] found, through a qualitative study conducted at a Swedish oncology department, that some patients' experiences of the long walk through the hospital corridors to the RT unit had an existential meaning for them, symbolizing danger or even death. Some patients described how they believed that the RT unit was hidden from the rest of the hospital, for this reason. However, patients also described positive experiences when entering the RT unit and finding a welcoming person in the reception to answer their questions, which helped them to feel secure and engaged [49]. To “be met” by someone was considered to be a part of a highly professional care system. An open waiting area with enough space for the patients to have some privacy but still feel that they have contact with the unit, including interaction with the staff walking through the waiting area was considered positive. The authors [49] conclude that the physical environment in a hospital setting is not only a place for caring. It is also a part of caring.

My clinical experience is that some cancer patients searching for information through the Internet may find a completely different scenario on the Internet images. Many pictures presented from companies producing RT equipment tend to paint a ‘prettier’ picture than that found in reality (picture 1a-c). On the Internet images, patients for instance tend to be fully dressed with their oncologist present in the room during treatment. Parts of the technical equipment are often hidden.

More than the high tech environment may affect patients undergoing RT. The RT preparations and treatment procedures also involve other routines that may increase vulnerability. During treatment the patients are left alone in the treatment room, monitored by the staff via a TV monitor. In many cases the patients are partly undressed and have their dentures removed. For some patients, it is necessary to mark the skin with a special pen. The staff may also use unfamiliar technical language, since there are many specific terms used between professionals in the daily RT process. The patients may also find the positioning uncomfortable, especially if they have to keep one position for long periods. These circumstances as well as the fact that a large number of staff (e.g. RT nurses/technicians, oncologists, physicists and engineers) is involved may cause uncertainty and distress for the patient. These circumstances may help to explain the vulnerability that H&N cancer patients have been found to experience [21]. Rose and Yates [21] conclude that if clinicians monitor the process and take action so that the daily RT is as short as possible, limit the number of staff involved in direct contact with the patient, and carefully inform the patients of all treatment procedures, patient vulnerability can be reduced.



Picture 1. The highly technical RT environment. Picture 1a (to the left) shows a H&N cancer patient in a fixation mask on the treatment couch with the RT equipment set-up for a lateral treatment field. Picture 1b (centre) shows a linear accelerator in a typical RT room. Picture 1c (right) shows an H&N cancer patient during daily RT set-up assisted by two RT nurses.

Photo: Picture 1a: Fotogruppen, Södersjukhuset. Picture 1b-c: Jim Sharp

2.2 THE SWEDISH MODEL OF RT NURSING

In Sweden, in contrast to many other countries, registered nurses with one-year postgraduate specific oncology/radiotherapy education plan, coordinate and deliver RT to cancer patients. In most other countries, RT technicians or radiographers, with a more technical education, perform these tasks. My experience is that most Swedish RT units practice a care delivery system in which one nurse is responsible for the care of each individual patient and their family during the RT period.

At the department where the current studies have been done, there is a H&N nurse case manager [50], responsible for the coordination of care, from time of diagnosis through treatment and through the ensuing rehabilitation phase. This system is, to my knowledge, unusual for RT-units in Sweden. The H&N cancer nurse case manager has a central role in the multidisciplinary team, working closely together with the RT nurses, oncologists, dental hygienists, dentists, speech therapists, dieticians, nurse assistants, social workers, physiotherapists and nurses on the oncology or ENT wards if the patients are admitted.

2.3 CONTINUITY DURING THE CONTINUUM OF CARE

H&N cancer patients in Sweden often have their first visit to the department of oncology within days after final diagnosis. Efforts are made to initiate the pre-treatment planning as soon as possible to avoid a delayed RT start. This intense period, illustrated in Figure 1, can be overwhelming for the newly diagnosed patient. Researchers have found that the need for structure and coordination is therefore important [51].

Continuity of care in nursing has been described in a review by Haggerty et al. [52] as a consistent approach between nurses which allows personalized care to patients during illness. Haggerty also defines continuity as how the individual patients experience the integration of services and coordination in a care setting. Cancer nurses have a key role in creating continuity of care for patients with H&N cancer. They follow the patients and their families through the trajectory of care and are in a

position to monitor progress. A report from The Swedish National Board of Health and Welfare [53] describes lack of continuity as the most common source of dissatisfaction with treatment and care among Swedish cancer patients.

It was previously common in some RT units to change the staff members who were involved in the individual patient's treatment from day to day. The rationale for this was to reduce the risk of treatment errors with the assumption that a nurse/technician might discover if a colleague has overlooked something or made a mistake in the treatment procedure. This approach was introduced before there were modern verification systems available to check and record the set-up procedure. I have found no empirical evidence supporting such procedures but on the other hand, there are data to support that the lack of continuity is a source of distress and discomfort for cancer patients in Sweden [53]. The regulations in Sweden also state that at least two staff members must be involved in every RT procedure, to reduce the risk for human errors. Today, continuity in the RT situation has been improved by the care delivery system described earlier, whereby one nurse is responsible for the daily treatment and cancer care involved for each patient and their families.

3 NURSING ISSUES AND CARING FOR PATIENTS WITH HEAD AND NECK CANCER

H&N cancer patients may need extensive support from nurses due to the effects of both the disease and the cancer treatment. If nurses are aware of the patients' life history and prior experiences, they may be able to improve quality of care when supporting and educating both patients and their family members. As described by McGabe [54], a nursing approach that is patient-centred (rather than task-oriented), focusing on the patients' and family members' involvement in the care, may improve the patients coping skills and the quality of care.

Since family members to H&N cancer patients have also been found to be deeply affected by their relative's disease and treatment [42, 51, 55], it may be important for them to be properly educated, informed and involved in the patients' care. Several qualitative studies [20, 21, 39, 56] on H&N cancer patients indicate that effective education that provides both patient and family members with information can reduce uncertainty and anxiety. Specific instructions for self-care may enable patients and family members to maintain their desired level of independence throughout the cancer treatment period.

3.1 THE HEAD AND NECK CANCER PATIENT – NURSE DIALOG ¹⁰

3.1.1 Information

Several researchers [39, 51, 58] argue that information regarding treatment procedures, expected effects and side effects are essential components of support and may reduce anxiety during treatment. Repeated information is considered important and may give the patient several opportunities to ask questions and/or discuss various issues during the different stages of the continuum of care.

Several studies exist on how to inform cancer patients prior to RT, some with conflicting results. Thomas et al. [59] found that patients receiving RT or chemotherapy were more satisfied with written information in combination with an information video than with only written material. Another study, by Harrison et al. [60], showed no improvement with a video as a complement to verbal information for H&N cancer patients. Kagan et al. [61] indicates that e-mail may be an alternative for improving information and communication between H&N cancer patients and clinicians, even if there are concerns regarding patients' privacy and risks of misunderstandings. Some researchers [51] indicate that most H&N cancer patients and their family members want to receive all information regarding care and treatment they can get, but these researchers also note the risk of information overload. Gaston et al. [58] found that written patient information should be delivered before the appointment rather than during it, to improve cancer patients' involvement in decision-making.

¹⁰ Interchange and discussion of ideas, especially when open and frank, as in seeking mutual understanding or harmony [57].

Empirical data [21, 62] shows that travelling to and from the hospital is one of the most common sources for distress among cancer patients. My experience is that sometimes these problems concerning daily travel are so essential to patients that it is crucial to solve this issue directly, so that the patients can relax and take in information regarding their treatment and care.

I have found that misconceptions about RT, such as becoming radioactive or losing all body hair, are still common, and that earlier experiences and beliefs about RT are important to consider when communicating with patients. Some patients may have heard ‘horror stories’ from older family members or friends about being badly burnt from RT. These misconceptions are of course not limited to patients with H&N cancer, but may be important for nurses to discuss, as patients may not bring up earlier experiences spontaneously. Research has shown that a large majority of cancer patients prefer to be given as much information as possible about their disease and treatment, regardless if the information is “good” or “bad” [63].

3.1.2 Communication

Moore et al. [20] found that communication between H&N cancer patients and clinicians may be insufficient. They also found that some patients felt that not enough effort was made to reach satisfactory communication between the multidisciplinary team and the H&N cancer patient, especially during the post-treatment period. In a study by van Wersch et al. [64], a care diary was found to be useful for improving information and communication for both H&N cancer patients and their families, and also to assess the individual patient’s need for information. Moore et al. also [20] found in their qualitative study that some H&N cancer patients underreported problems experienced in their contact with clinicians as a result of poor communication. Ledebøer et al. [65] concludes that open communication between H&N cancer patients and their families has a positive effect on the rehabilitation process.

3.1.3 Involvement and decision-making

Edwards et al. [66] found in a British study, that H&N cancer patients wish to be more involved in decisions made regarding their care and treatment. According to Swedish law [67], cancer patients have a right to participate in informed decision-making regarding care and treatment. Supporting a patient’s choices has been identified as an important dimension of cancer nursing [68]. If patients are involved in decision-making, they may be more likely to be satisfied and to comply with health education [56]. Kagan et al. [69] concludes that attention to rehabilitation should be an on going process that is coordinated by nurses, and which functions as a way of involving patients and reducing the risks for complications [69, 70]. Gaston et al. [58] found in a review of 172 papers on decision-making among cancer patients, that most patients with advanced cancer wished to be fully informed and that a majority wanted to be involved in decision-making. Gaston et al. concluded that women and younger cancer patients were more likely to take an active part in decision-making.

Treatment options should, of course, be discussed thoroughly with patients and their families, but in my experience, patient involvement among H&N cancer patients may also consist of “simple” matters such as having an impact on the schedule of daily appointments, which might give the patient a chance to retain some control over their

daily living situation. The scheduling of treatment can also be a source of stress and even if it may be difficult for RT-units to be completely flexible with regard to treatment times, the patient's daily circumstances and routines should be taken into consideration. My experience is that well-informed and involved patients are more likely to avoid RT interruptions. This clinical impression is supported by a qualitative study by McLane et al. [56]. They conclude that H&N cancer patients and their families, who are well informed and encouraged to be involved in decisions regarding care and treatment, may improve their coping skills resulting in less anxiety and worry. Bottorff et al. [68] conclude that the cancer nurse's role is to provide information, clarify, assist and listen to the patients and their families during the process of making these decisions. Buffum [71] conclude from a qualitative study aiming to illustrate the empowering process, that cancer patients may become passive consumers of health care and may therefore also be passive in decision-making related to cancer treatment. Buffum defines empowerment as a process that promotes individual mastery and control over life and important decisions, and describes a four-step process to achieve empowerment among cancer patients as consisting of: 1) reflection over the patient's current situation, 2) determination of causes of problems, 3) exploring consequences, and 4) development of an action-plan.

3.1.4 Self care strategies

McLane et al. [56] argue that a systematic self-care program, even if time-consuming for the staff involved, could improve communication between both H&N cancer patients and their families and also between the patients and clinicians involved. To ensure that patients and their families have sufficient support once RT is over, nurses and other clinicians may initiate the process of rehabilitation at diagnosis [56]. Mok et al. [72] describe in a qualitative study, that cancer patients find "inner strength" through connection with others—not only family and friends, but also health care professionals, which may be particularly important to recognize when caring for H&N patients who may have limited social networks. The patients' experiences of being empowered were described in the same study as enhanced by good communication with the multidisciplinary team. Mok et al. [72] also conclude that empowerment does not necessarily depend on direct decision-making, but rather on allowing cancer patients to control to what degree they will be involved in decision-making regarding treatment and care.

3.2 MANAGING SIDE EFFECTS

Management of RT related side effects is essential for nurses, to be able to deliver the intended RT dose on time, since treatment interruptions may have negative effects on the outcome. Nursing research on patients with H&N cancer undergoing RT tends to focus on pain, eating and swallowing problems [73-75], which are salient problems in this group. My experience is that many oncology departments therefore have well established care plans for these matters, including regular consultation with a dietician, weight checks, pain management programs, nutritional supplements and sometimes tube-feeding.

Eilers [38] argues that the management of pain and oral care are important nursing issues, since oral pain and severe oral mucositis have been found to cause great discomfort for patients and may lead to treatment interruptions [37]. Both Duncan et al. [37] and Eilers [38] points out that severe oral mucositis is usually the side effect

that limits the RT dose. Care plans including systematic nursing assessment and care, instructions for self care, documentation and follow-up have been described as effective tools for nurses to help patients manage these problems [38, 76, 77].

The assessment and management of radiation skin reactions (picture 2 a-c) for H&N cancer is a great challenge for RT nurses, since serious skin reactions might lead to infections with great impact. A great variety of local remedies are now in use and many RT units have a tradition of using different skin care products with little or no documented effect. A randomised double-blind trial by Wells et al. [35] on 357 patients (breast, rectal and H&N cancer) showed no significant difference in erythema between patients using aqueous cream or sucalfate cream compared with patients using no cream. The authors also conclude that water based mild skin lotions may still be recommended, not to reduce erythema, but to keep the skin soft and moist.

An old tradition among some RT nurses has been to instruct the patients not to wash the skin at all or avoid the use of soap in the irradiated area during the treatment period. The rationales for this was that soap would irritate the sensitive irradiated skin and also remove the skin marks used for the daily set-up procedure. However, several randomised trials have shown that washing the irradiated skin area with mild soap and water does not increase the risk of severe skin reactions [78-80].

The dry and/or moist desquamations (picture 2b-c) may be painful and itching [39]. Mild hydrocortisone cream has been frequently used but there is conflicting evidence about the effects [81, 82]. There are some indications that a more potent steroid cream could be more effective. A randomised double-blinded study [83] showed significantly reduced erythema (assessed using a reflectance spectrophotometer) for breast cancer patients undergoing RT, using a potent corticosteroid cream (mometasone furoate) compared with patients using placebo. Despite these objective findings, this relatively small study (n = 49) failed to show any significant reduction of subjective symptoms, such as itching, burning sensation or pain. This study also lacked a long- term follow-up of the effects of using this potent corticosteroid cream for this relatively long time period (five weeks) on irradiated skin.

Skin care advice normally includes recommendations to avoid trauma or friction from tight clothes, avoiding scrubbing or perfumed skin products and sun exposure. Normally patients are recommended not to use any skin products prior to the daily RT, to avoid a possible build-up effect, which might worsen the skin reaction. For the same reason, all kinds of taped dressings should be avoided during RT. Today some RT units [84] use more modern silicon adherent dressings, which may not irritate the skin or increase the build up effect, but more research is needed to document their effects. According to Wells et al. [39], nurses need to pay extra attention to patients with known high risks for developing radiation skin reactions (e.g. smoking and high body mass index) and self-care strategies and education is therefore considered essential.



Picture 2. Radiation skin reactions, showing the individual differences. Picture 2 a (to the left) shows radiation induced erythema. Picture 2b (centre), shows erythema in combination with dry desquamation. Picture 2c (to the right) shows erythema in combination with dry and moist desquamation. All patients above were photographed after 38 Gy (during the fourth RT week).

Photo: Fotogruppen, Södersjukhuset (2a-b), Maud Ek (2c).

Communication and speech have also been found to be major problems for H&N cancer patients undergoing RT [21]. The multidisciplinary team may therefore include a speech therapist, who is involved at an early stage for assessment and treatment [85].

As described earlier, fatigue [21] has been found to be a very common and probably underestimated symptom for patients receiving RT. The causes for fatigue are not well known, even though a lot of research has been conducted (e.g. [86-89]) concluding that fatigue is a complex symptom, with multifactorial causes. There is some evidence on how to manage fatigue, including information, preparation and physical activities [90]. Ahlberg et al. [90] conclude that it is important for nurses to assess the levels of fatigue continuously during and after RT, since fatigue could have physical explanations, such as anaemia, which may be treated effectively.

The post-treatment period has also been found to be a particularly vulnerable time for some H&N cancer patients [21, 33, 39]. This is the period when the daily RT stops and may therefore also mean the end of the patient's daily contact with members of the multidisciplinary H&N team. As mentioned, the acute side effects peak at the end of RT or during the first few weeks past RT, and some patients described this as the time they started to grasp all they have been through since diagnosis [39]. It may be too early to evaluate the outcome of the treatment and the future is therefore far from clear. To be neither healthy nor cured can be a difficult situation for the patients. During this period, many patients may need extra nursing support but might not seek help. Wells [39] found that some H&N cancer patients described that even if their symptoms were distressing, they would not want to "take up the valuable time" of the multidisciplinary team. One explanation given was that they viewed their situation as "too insignificant to be important". This was also later supported by Moore et al. [20] who also found that one explanation given for underreporting problems was the H&N cancer patients' fear of receiving more bad news.

The communication and collaboration between cancer centres and community care, such as advanced home care teams, district nurses or GPs may be essential, especially for patients with H&N cancer and their families. They constitute a relatively small group of patients leading to a clear risk that district nurses or other clinicians have little or no experience of caring for patients with H&N cancer. I argue that cancer nurses at the RT-units and oncology out patient clinics therefore must play an important role in creating flexible and accessible support for the H&N patients during this vulnerable period. This is also supported by Moore et al. [20] who found that some H&N cancer patients express a desire to discuss experiences and psycho-social issues after cancer treatment and that these needs were not met at the strictly medical follow-ups.

Side effects such as dysphagia, oral mucositis, xerostomia and fatigue may result in weight loss and discomfort [21]. Öhrn et al. [77] found that 94 % of H&N cancer patients had oral symptoms one month after completing RT. Rose and Yates [21] found that many H&N cancer patients had severe side effects from RT, four weeks after completing RT. These complications may, if not dealt with, delay surgical treatment, which could negatively affect the patient's prognosis. Clinical experience at our department, not yet systematically studied, suggests that a follow-up close to termination of RT, for instance at a nurse led out-patient clinic, may help the patient manage these side effects and help prepare the patients and their families for the upcoming surgery. Campell et al. [91] found that nurse-led clinic for RT patients provided improved quality of care and continuity and the authors conclude that this was an important complement to medical care. Similar findings were also reported by Faithfull et al. [92].

When the acute side effects of the RT have past, the patients face the risks of permanent changes, such as xerostomia. Symptoms like fatigue, altered taste and appetite can last for several months [37]. Appropriate and timely information to the patients is important, but also difficult due the great individual differences between patients.

Living with the threat of cancer recurrence can be a great source of worry and anxiety for patients [21]. I have found that many H&N cancer patients describe this period as a long wait with frequent medical follow-ups, which are said to be both reassuring but also stressful. Having a monthly appointment with an oncologist and/or ENT specialist may feel secure but also includes the potential for new bad news every month. I have found patients during the follow-up period to be especially sensitive to the occurrence of possible new symptoms. The time allocated for medical follow-up appointments is short and the focus is often on evaluating the treatment and examining the patient for possible recurrences [20].

3.3 POSITIONING AND FIXATION

A source of worry and anxiety specific to the RT situation is the use of an immobilisation system [21], such as thermoplastic face masks. These masks are typically moulded (picture 3) only days after diagnosis and pre-treatment dental care, to allow time for 3-D pre-treatment dose planning. The masks are thus often made during a stressful period for the patients, who also have busy pre-treatment schedules (Figure 1).

Claustrophobia during RT for H&N cancer patients has not been studied extensively. Most studies on fixation techniques, such as thermoplastic masks, has focused primarily on reproducibility [25, 27, 93, 94]. We found no published data that focused on H&N patients' experiences with immobilization systems during RT. However, I have seen treatment interruptions due to claustrophobia as a clinical problem, which in the worst case can lead to a more limited choice of treatment options.

Rose et al. [21] support this with their finding that some H&N cancer patients rated the immobilization mask as being one of the worst experiences during their illness.



Picture 3. The molding process of a thermoplastic mask for immobilization of an H&N cancer patient prior to RT. Photo: Jim Sharp.

Various coping techniques have been used to reduce anxiety during these procedures, such as listening to music for relaxation or hypnosis, but I have found no evidence of the effect of such techniques.

3.4 PSYCHO-SOCIAL ISSUES

Several psychosocial issues are of particular concern for patients with H&N cancer and their families [6, 21, 39, 95]. It is important for nurses to address these issues and to be aware of the fact that the patient might have great concerns, which they may be reluctant to bring up in contact with health care professionals. For example, Moore et al. [20] found that some H&N cancer patients experience that they have lost their feeling of security in life, and that these feelings may be persistent even years after cancer treatment and disease free follow-up. Moore and colleagues also conclude that the helplessness some patients feel at the time of diagnosis may negatively affect their capacity to cope partly caused by the disease but also by earlier life experiences. The authors suggest that better communication with clinicians in the multidisciplinary team may improve the patients coping skills.

3.4.1 Finances

Duffy et al. [5] found that many H&N cancer patients in the US come from low-income backgrounds, e.g. low-income jobs, unemployment, long-term sick leave or retirement. Feber [8] describes similar circumstances among H&N cancer patients in England. This is also a concern regarding H&N cancer patients in Sweden, in my experience. Even if most of the costs for health care in Sweden are covered by national insurances, there are still considerable initial costs for the patient. These initial costs include payments for consultations with clinicians, medications and travel costs. After paying up to a certain level, most health care and related costs (medications, travel) in Sweden are free of cost for the patient for one year. Some patients might find these economic issues embarrassing to bring up, especially before they have established a good relationship with their clinicians. Nurses may offer support, by suggesting contact with and referral to social services or helping the patient applying for financial aid from various sources, such as cancer societies or help organizations [55]. Many cancer centers have social workers, with experience and special education to deal with cancer related social or psychosocial issues. I argue that there is a need for cancer nurses and other clinicians to be observant and offer these services to all patients and their families.

3.4.2 Employment

Another source of worry for H&N cancer patients under retirement age, might concern work situations and employment. According to Rose and Yates [21] this was a common problem for H&N cancer patients, four weeks after completing RT treatment. Wells et al. [39] describe how many H&N cancer patients are unable to work both during the diagnostic period, the treatment phase and the rehabilitation phase and that some patients might not even be able to go back to their old job, due to long term side effects or complications. Other patients are able to work full time or part time during parts of this period. Studies has shown [5, 8, 96] that unemployment might be relatively high among H&N cancer patients, even before diagnosis, and some patients may not have a job to go back to. My experience is also that some patients also express concerns regarding different issues in the working environment, for instance smoking among colleagues. For patients who have managed to quit smoking during treatment and rehabilitation, it might be difficult to go back to a work environment were colleagues are smoking.

3.4.3 Social and emotional relations

The social and emotional relationship with family, friends and colleagues might be greatly affected by H&N cancer and treatment [21], due to disfigurement, side effects, altered body image, speech problems and also by existential worries or reduced self-esteem [39, 51]. Some patients live isolated even before the diagnosis and their situation may not have been improved through the cancer treatment. In my experience, patients that quitting smoking or drinking during their sickness sometimes have difficulties in socialization with old friends, that might still be smoking and/or drinking. Nurses may pay attention to these problems and many hospitals offers social support programs that might be helpful. It might also be reassuring for the patients to meet others in similar situations [39] and H&N cancer patient organizations may play an important role here. However, Moore et al. [20] found that H&N cancer patients might need to be approached repeatedly, since they may not initiate such contacts spontaneously but might later wish they were encouraged more to join.

3.5 SMOKING

Cigarette smoke contains carcinogenic substances such as tar, carbon monoxide (CO), tobacco specific nitrosamines and benzene [97]. Studies have shown [13, 14, 98] that a majority (85-90 %) of H&N cancer patients are current or ex-smokers and that smoking may have a negative effect on treatment outcome [99] and general health [32]. Two studies with self-reported data has shown [9, 100] that approximately 1/3 of all patients with H&N cancer patients continue to smoke past diagnosis and treatment. As mentioned, research have shown that smoking may increase the side effects of RT [32, 35, 36]. Secondary prevention may therefore be important to reduce the risk on new smoke-related cancer and complications from cancer treatment, but also to give best possible conditions for the cancer treatment to be effective.

3.6 NICOTINE ADDICTION

Addiction has been defined as a process whereby a behaviour, that can function both to procure pleasure and to provide escape from internal discomfort, is employed in a pattern characterized by; 1) recurrent failure to control the behaviour and 2) continuation of the behaviour despite significant negative consequences [101].

Most tobacco consumers are addicted to nicotine, which is a substance found to be strongly addictive but not carcinogenic [102]. Nicotine has been described to have both physical and emotional elements and to have a number of effects on mood and cognitive function. Le Foll et al. [103] found that smokers report positive effects of nicotine, such as improved concentration or performance on certain tasks, relaxation and stress reduction. With other words, nicotine could improve a smokers' performance when they are tired and relax them when they are stressed.

The physical elements, causing withdrawal, may be treated with alternative nicotine products (ANP) [102]. There are several ANP, such as patches, chewing gums, lozenges, inhaler and spray, commercially available today. In Sweden and many other countries, these products are sold at pharmacies over counter and no prescription is needed. My clinical experience is that many H&N cancer patients find them costly and therefore are reluctant to buy them.

Swedes, in particularly men, have a strong tradition of using a non-smoking tobacco product, known as snus. In a statistical report, commissioned by the European Smokeless Tobacco Council [104], the prevalence of daily snus consumers in Sweden was 23 % among men and 3 % among women. The same report describe that 15 % of Swedish men and 17 % of Swedish women are smoking on a daily basis. Swedish moist snus contains primarily of ground tobacco, sold in portions or as loose tobacco and placed under the upper lip. Swedish snus have been found [105] to contain low levels of carcinogenic tobacco specific nitrosamines. To use snus in smoking cessation program might be controversial but studies have failed to show that snus causes cancer [11, 106, 107]. Even though there are health risks involved, Fagerström and Schildt [108] argue that the negative health effects from snus are far less than those from smoking. Swedish snus may therefore be a safer alternative to cigarette smoking for H&N cancer patients with high nicotine addiction, that find it difficult to stop using nicotine.

Cancer patients who continue to smoke after their diagnosis may be strongly addicted to nicotine and may also have other health risk factors, found [109] to make smoking cessation more difficult, and may therefore be in need of suitable interventions.

The level of nicotine dependency could easily be tested, using the Fagerström Test for Nicotine Dependency (FTND) [110]. The test contains six questions on smoking habits and results in a score from 0-10, indicating what level of nicotine dependence a smoker has.

My clinical impression is that health care professionals often neglect nicotine addiction even if many hospitals and other care settings today are smoke-free. Smoke-free environments has been shown to benefit smoking cessation [111] but may also be problematic to implement [112, 113]. If the nicotine addiction is neglected there is an obvious risk for serious withdrawal symptoms or smoking in bathrooms or even beds in hospitals or other care settings.

3.7 SMOKING CESSATION

Other than preventing smoking, smoking cessation has been described [114] to be the most effective strategy to decrease the number of smoking related cancers. Sanderson Cox et al. [115] conclude in a review on nicotine dependence for cancer patients, that smoking cessation after a cancer diagnosis may improve both physical and mental health and, for H&N cancer patients, even improved survival rates. There are some studies published on the effect of nurse-led smoking cessation for cancer patients [116-119]. These studies all include control groups receiving 'usual care' and self reported smoking status was confirmed with biochemical tests. Even if the results in all these relatively small studies were promising, they all failed to show significantly higher quit rates among the patients in the intervention groups.

Rice and Stead [120] showed in a recent Cochrane review on nursing interventions for smoking cessation (not specifically for cancer patients) that 20 out of 29 randomised studies showed improved results in the intervention groups. Rice and Stead conclude that the challenge would be to incorporate smoking cessation interventions into standard care. My clinical experience is that smoking cessation has not yet become a standard part of cancer nursing, and more knowledge on intervention programs tailored for different groups of cancer patients are needed. Rice and Stead [120] also conclude that for patients with smoke-related health problems, nurse-led smoking cessation intervention may be more successful than for patients without known smoke-related health problems. To quit smoking successfully during cancer treatment might also improve the patients' self-efficacy and motivate them to adopt a healthier lifestyle in general. This may be particularly important for H&N cancer patients, since research has shown [121, 122] that 10-12 % of the patients develops a secondary cancer during the first three years past first cancer diagnosis.

I have found that there are a number of specific circumstances for cancer patients that want to quit smoking, compared to other smokers. Cancer patients are facing a life threatening disease, which may mean that their desire for stress-relieving nicotine is greater than at during other periods in life. Another specific circumstance may be the urgency in cessation that might add ever more pressure on the patient. In some other smoking cessation programs [123] it is recommended to set a quit date several weeks after a decision is being made to give up smoking. The preparation period could then be used to cut down on the number of cigarettes per day and to improve the motivational levels etc. For H&N cancer patients, the stressful pre-treatment period may be used as a quitting smoking preparation period, which may add to the stress even more.

On the other hand, some studies have indicated [124] that cancer could be a 'teachable moment' whereas smokers might be more motivated [125] to quit smoking and therefore also more successful in their attempts. Specific teachable moments (e.g. hospital admissions and time for diagnosis) for cancer patients to quit smoking has been suggested by McBride et al. [124] and by Sanderson Cox et al. [115]. McBride et al. [124] also point out that clinical feedback, for instance if/when the levels of CO in expired air are dropping, could be teachable moments and the authors recommend to also involve smoking family members in these tests.

Attitudes to smoking among cancer patients may also important to address. A common misconception, both among patients, family members and even clinicians are that it is too late to quit once you have been diagnosed with cancer. Sarna et al. found [126] that cancer nurses have little tradition in involving themselves in

smoking cessation, due to lack of training, and a fear of destroying their relations with the patients, even if they believe that smoking cessation is important and should be included in cancer nursing. Sanderson Cox et al. [115] points out that some health care providers are of the opinion that cancer patients who continue to smoke after diagnosis are unmotivated and not susceptible to smoking cessation. The same authors argues that there is evidence that cancer patients are interested in smoking cessation but may need professional assistance.

Research has showed that the recommendations from clinicians to quit smoking are seldom enough. Lerman et al. [127] conclude in a recent review (not focusing specifically at cancer patients) that behaviour therapy alone was associated with quit rates of 7-20 %. Quit rates for ANP alone were reported to vary from 10-44 % (at 6 month follow-up) in the same study. The authors also conclude that a combination of ANP and counselling generally improve quit rates. This is also supported by other researchers [120, 128].

3.8 CHANGING BEHAVIOUR

Newly diagnosed H&N patients may have several areas (e.g. smoking and alcohol habits, isolation and/or poor food intake) where a changed behaviour could be beneficial for the future health. During this overwhelming period, when existential issues might cause worry and anxiety, it may be difficult for the patients to see the long- term benefits that these behaviour changes could gain.

There are several models for behaviour change described in the literature. Most of them have been tested on different types of behaviours, such as smoking, alcohol or other types of drug abuse and could be used for nurses and other clinicians. Our nurse-led intervention program for smoking cessation (paper III and paper IV) was influenced by the following three models for behaviour change.

The Trans Theoretical Model of Change, was developed by Prochzka et al. [129] and describes behaviour change as a process in five stages of readiness to change (Table 1).

Table 1. Brief description of The Trans Theoretical Model of Change

Stage		
1	Precontemplation	a smoker have no intentions to quit
2	Contemplation	a smoker is considering to quit during the following six month
3	Preparation	a smoker is actively planning to quit within the next month
4	Action	a smoker just have stopped
5	Maintenance	the ex-smoker has been smoke free for six month and have developed coping skills to remain abstinent

The Trans Theoretical Model of Change has frequently been used in smoking cessation programs, both among H&N cancer patients [130] and also among patients with lung cancer [115]. The goal with this model is for the clinician to assess what stage of change the smoker is in and to help him/her advance in the stages of readiness to change. The higher stage, the more likely the person is presumed to

succeed. The different stages require different approaches from the clinician. Sometimes this model also includes a sixth stage, Termination.

5A [102] is a program for smoking cessation developed by The United States Public Health Service, in an effort to reduce cigarette smoking. The program includes the five A:s, described in Table 2. The model was first introduced as 4 A:s, and was later complemented with the 5th A (Assess). The 5 A program has been widely used and is considered to be easy to implement in most care settings and not time consuming. In the 2nd A (Advice), clinicians are recommended to give a strong and clear advice to smokers to quit. This message should be personalized for each individual and includes information on the impact on continues smoking in a given situation.

Table 2. Brief description on the 5 A program

Ask	every patient about their tobacco use
Advice	all smokers to quit
Assess	smokers willingness to quit
Assist	with support, treatment and referrals
Arrange	follow-up

Motivational Interviewing was developed by Rollnick and Miller [123] as a model for behaviour change in the treatment of alcohol abuse. The model has later been used in the treatment of nicotine dependency and other types of substance abuse [131]. The rationale for this model is to help people to explore and resolve ambivalence feelings concerning their nicotine dependency and the model suggest a negotiating approach rather than an advice giving approach.

The key issue in Motivational Interviewing is described by Rollnick and Miller [123] as a “meeting amongst experts”. The clinician or consultant may be an expert in cancer care or smoking cessation and the patients or clients are experts on themselves. They have the insight, experience and knowledge required to make a decision, plan and go through with a behaviour change attempt.

In summery, the data reported and discussed in the following four papers focus on different aspects of nursing care for H&N cancer patients undergoing RT.

4 AIMS

The general aims of this thesis, consisting of four papers, were to investigate how to improve the nursing care, focused on patient information, communication and involvement, patient positioning, reproducibility and comfort, and smoking cessation for patients with H&N cancer undergoing RT.

- Paper I** To study the helpfulness of care diaries for patients with H&N cancer receiving RT, their family members and clinicians in different care settings.
- Paper II** To compare two types of thermoplastic Posicast ® facemasks in terms of reproducibility of patients' position over time, patient tolerability and comfort, and early skin reactions during RT for H&N cancer.
- Paper III** To describe a nurse-led smoking cessation program and to explore how both H&N cancer patients and the nurses caring for them experience the program.
- Paper IV** To evaluate the effectiveness (proportion of smoke-free patients) of a nurse-led smoking cessation program for patients with H&N cancer, with a follow-up of one year.

5 MATERIAL AND METHODS

This thesis consists of three papers (paper I, II and IV) using a quantitative design and one paper (paper III) using a qualitative study design.

5.1 SAMPLES

The patients and family members in all four papers were recruited, after informed consent, from a department of oncology at a university hospital in Stockholm.

In paper I, investigating the usefulness of care diaries, the sample consisted of 42 H&N cancer patients, 28 family members and 47 clinicians (from different care settings involved in the care of H&N cancer patients). The patients were recruited consecutively and were asked to also give one questionnaire to a family member. A number of questionnaires were sent out to different settings involved in the care of H&N cancer patients, but no questionnaires were addressed to a specific individual clinician.

In paper II, comparing thermoplastic face masks, the sample consisted of 260 H&N cancer patients, who were recruited consecutively. Patients with nasopharyngeal cancers were excluded. Two hundred forty-one of these patients could be evaluated.

In paper III, exploring nurse and patient experiences of smoking cessation, the sample consisted of the first 13 patients recruited to the smoking cessation intervention (also included in the sample in paper IV). These were H&N cancer patients who were active smokers and were planned for curative RT. The sample also included two RT nurses, with long experience of cancer care.

In paper IV, evaluating the effectiveness (proportion of smoke free patients during RT and follow-up) of a smoking cessation program, the sample consisted of 50 consecutively recruited H&N cancer patients, who were active smokers and planned for curative RT. The patients were followed for one year.

5.2 DESIGN ISSUES

5.2.1 Randomisation procedure (paper II)

During the pre-RT phase in the second study, the patients were randomly assigned to one of the two types of mask. The randomisation was performed by telephone contact with an independent central office, where the patients' personal identification number was recorded before the treatment allocation was revealed. The randomisation was done using balanced lists prepared by use of the permuted block technique, to keep the numbers of patients in the groups balanced at all times.

5.2.2 Reproducibility (paper II)

Set-up errors were measured to assess the reproducibility of the two types of thermoplastic masks. Port films and simulator films were compared on two occasions for each patient (after the initial RT and four weeks into RT). An experienced

oncologist and physicist did these comparisons manually. Required shifts were performed according to specific instructions in the study protocol. Comparing the actual treatment table positions over time also assessed the reproducibility. The RT nurses performed this assessment weekly, and required adjustments (≥ 1 mm) in the table position (vertical, longitude and latitude) were documented.

5.2.3 Smoking cessation program (paper III and IV)

The nurse-led smoking cessation program used in paper III and IV consist of the following components. A more detailed description is available in paper III.

5.2.3.1 Increased nurse involvement

The RT nurses involved in these studies followed the patients closely during the smoking cessation process. These nurses were further educated in the different component of the program and also had weekly meetings to discuss issues related to the patients in the program.

5.2.3.2 Behavioural change

The program was based on three models for behaviour change. For further description, see section 3.8.

5.2.3.3 Alternative nicotine products

The patients received cost-free supplies of ANP on a weekly basis, for ten weeks. First a test-pack of the different products (patch, gum, lozenge and snus) was provided, and the patients could then choose the products they preferred. The nurses instructed the patients as how to use the ANP products and documented their choices.

5.2.3.4 Carbon monoxide

Research has indicated that biochemical tests are more reliable than self-reported smoking status among patients with H&N cancer [132]. The most commonly used biomarker is CO in expired air and saliva or serum cotinine. Cotinine is regarded to be more reliable than CO, but not practical to use in smoking cessation programs where ANP are used. CO has relatively short half-life, and after a few days up to a week being smoke-free none or very low levels of CO can be detected in expired air. The CO monitors are easy to use in a clinical setting and the patients could get instant feedback on their current smoking status. The instrument used in paper III and IV was the Bedfont Smokerlyzer[®]. The test was performed weekly during the RT-period (at least five tests) and then after three, six, nine and twelve month during follow-up. To be tested as smoke free the results had to be 0-4 ppm (parts per million) CO in expired air.

5.2.4 Skin assessment (paper II)

There are several skin assessment scales, such as The NCI (National Cancer Institute) toxicity criteria, RTOG/EORTC (Radiation Therapy Oncology Group/European Organization for Research and Treatment of Cancer) assessment scale, The RISRAS scale (Radiation Induced Skin Reaction Assessment Scale) and the WHO (World

Health Organisation) scale of acute and sub acute toxicity to measure acute skin radiation toxicity or side effects. In paper II, we used the WHO scale of acute and sub acute toxicity [133]. This scale was initially developed and aimed more specifically for use in conjunction with chemotherapy, but was later further developed to also be suitable for grading toxicity caused by RT. The WHO scale, with scores ranging from 0-4, had been used in earlier clinical trials at our department, and were therefore already well known among the staff. Weekly assessments, jointly by an RT nurse and oncologist blinded to type of mask the patient was allocated for, were performed and documented during the RT period.

5.2.5 Qualitative design (paper III)

In paper III, a qualitative, descriptive approach was used to obtain knowledge on how H&N cancer patients and nurses caring for them experienced the smoking cessation process. Qualitative research has a relatively short tradition in medicine, but is more commonly used in other fields of research, such as nursing, sociology and psychology [134].

Patton [135] (p. 10) describes qualitative research as a way of “illuminating the people behind the numbers and putting faces on statistics”. According to Patton, the purpose of qualitative research is to gain an insight into subjective experiences, for example, when little is known about a phenomenon.

In qualitative studies, the researcher is intimately involved in the research process. Normally a relative small sample is used, but each respondent contributes in-depth data. The purpose of the qualitative approach used here was not to draw directly generalised conclusions but rather to describe in depth a variety of experiences, related to a phenomenon, to help better understand the processes at work in the smoking cessation intervention. One typical sampling strategy in qualitative research is to study a small number of people with heterogenic qualities that might affect their experiences [134]. In the study presented here, patients were recruited consecutively until we felt sufficient variation had been achieved.

There are three types of data collection are mainly used in qualitative research; interviews, direct observations and written documents [135]. Written diary notes were used for data collection in paper III.

Qualitative research generates large quantities of data. Analysis of qualitative often begins with the researcher/s reading through the interview transcripts or other written documentation repeatedly to obtain an overall impression [135]. That stage is normally followed by a stage of organizing and coding data. The researcher/s then often seeks to identify themes or categories and explore the relationships between these categories or themes. The findings are presented using quotes from the original data [136] to demonstrate the relationship between empirical data and description or interpretation. A commonly used method for analysing qualitative data is content analysis. A version of content analysis is Framework analysis or Framework approach. This method was used in paper III and is described below.

My experience is that it is sometimes difficult for the reader to follow the analytic process in qualitative research. To explain how categories or themes are developed from the collected data and succinctly present this data using words as the units of analysis can be challenging, especially since many scientific journals have strict limits on the length of the manuscripts.

5.3 DATA COLLECTION

5.3.1 Quantitative data (papers I, II and IV)

5.3.1.1 Questionnaires

For paper I, a questionnaire with nine questions regarding the care diaries, was developed to evaluate the helpfulness and use of the diaries. The questionnaire had seven questions with Likert-type rating scale options (4-to 5 point scale options) for responses. It was sent to H&N cancer patients and their family members and also to clinicians in different care settings. The questionnaires also contained two open questions.

For paper II, a questionnaire including five questions was developed by the authors to assess H&N cancer patients' experiences and the tolerability of the two types of face mask used as immobilization device (the HM or the HMS) during RT. The patients were asked by the RT nurses to respond to these questions weekly during the treatment period. The questions were formulated with yes or no response options and included questions on pain, fit, discomfort, claustrophobia and mobility of the head within the mask during RT.

5.3.2 Qualitative data (paper III)

5.3.2.1 Diary notes

The qualitative data in paper III was collected through diary notes from patients and nurses. The diaries were focused, in the sense that both patients and nurses were instructed to focus their notes on issues related to the smoking cessation process. The diaries were unstructured, since they were blank pages with no pre-existing questions, numbers of pages expected per day etc. The intent of the unstructured diaries was that both patients and nurses should be able to express themselves freely. Diaries was also considered suitable for this group of patients that might have temporary or permanently speech difficulties that may make other types of data collections, such as interviews, difficult.

5.4 ANALYSES

5.4.1 Quantitative data analyses (papers I, II and IV)

Paper I. The returned questionnaires were summarised and the results were presented with descriptive statistics for each question. The chi-square test was used for differences in proportions. The respondents were encouraged to write down comments after each question. No specific analysis was performed based on these comments, but representative comments were chosen to illustrate typical responses about the impact of the care diary.

Paper II. The analysis was performed according to the intention-to-treat principle. No interim analysis was performed. Comparison of proportions of events in the two groups was presented as absolute differences (per cent) with 95 % confidence

intervals. Chi-square test of independence for categorical variables and two-sample t test for continuous variables were conducted. All p-values are two-sided.

Paper IV. The results of the intervention were presented as the percentage of smoke-free patients during the RT period and the percentage of smoke-free patients after one year. Percentages were reported with associated exact 95% binomial confidence intervals. The comparison of the two groups (smokers versus non smokers at the one year follow-up) was based on the Mann-Whitney test for continuous data and on Fisher's exact test for categorical data.

5.4.2 Qualitative data analysis (paper III)

5.4.2.1 Framework analysis

One way of achieving structure in the analysis of qualitative data is through an approach called 'Framework approach' or 'Framework analysis', which is a version of content analysis developed by Ritchie and Spencer in the 1980s [137]. The method involves summarizing, organizing and describing qualitative data within a thematic framework [136-139]. The method was originally developed to analyse interview data, but has also been used to analyse unsolicited diary notes [140]. The method involves a systematic, visible and defined procedure of sifting, sorting and charting the collective data to key issues and themes. I describe the analytic process using in paper III below, using terminology derived from the five stages of the Framework approach [137]:

5.4.2.1.1 Familiarization

As first author, I transcribed the hand written diary notes from both patients and nurses. Since the nurses wrote notes regarding all patients, their diaries were compiled in to one diary for each patient. I read and re-read the transcribed text several times to gain an overview. During the reading process I made notes on key issues and recurrent themes.

5.4.2.1.2 Identifying a thematic framework

As a thematic framework, preliminary categories (or a priori issues) were identified through an earlier literature review [141]. An index was created with the preliminary categories (insight, motivation, behaviour change, addiction and environment) used as headings. The analytic process is also shown in Figure 1 in paper III.

5.4.2.1.3 Indexing

The preliminary categories of the thematic framework are then applied to the collected data, using a numeric system to represent the categories. Some text segments were relevant for more than one preliminary category and were then indexed to multiple categories. New categories were also developed since the a priori categories were not sufficient to index the content.

5.4.2.1.4 Charting

The indexed text was lifted out of the original text and was rearranged under the appropriate heading/category.

5.4.2.1.5 Mapping and interpretation

After all the data has been charted into the thematic framework, the author defines key characteristics and concepts of these categories.

An oncology consultant nurse with prior experience of qualitative research independently reviewed the analytic process. This led to further revision. The second author (CT) was asked to participate in continued data analysis and documentation. She analysed subsets of the raw data for further validation of the analysis and findings. Both authors developed the analysis further. The final analysis resulted in the following main categories, *Patient- nurse relationship*, *Factors facilitating or hindering behaviour change* and *Drug (ab)use*.

5.5 ETHICAL CONSIDERATIONS

The prognosis for H&N cancer patients is sometimes poor and the remaining lifetime may be limited. Patients in a palliative situation were therefore excluded from paper I, III and IV. In paper II a small number of patients (n = 10) received palliative RT. The use of a thermoplastic mask was necessary anyway and patients planned for palliative RT was therefore not excluded. The ethical considerations in paper III and IV concerns possible interfering with patients' lifestyle choices. We considered the possible benefits of smoking cessation to have such a positive impact that these risks were acceptable. All papers included in this thesis were approved from the relevant ethical board.

6 SUMMARY OF FINDINGS

6.1 PAPER I (CARE DIARIES)

Questionnaires were collected from 42 H&N cancer patients, 28 of their family members and 47 clinicians. A majority of the patients were men (n = 30, 71 %) and a majority of the family members were women (n = 22, 79 %). The largest group of clinicians were nurses (n = 33, 70%), but there were also responses from physicians (n = 7, 15 %), dieticians (n= 4, 9 %), dentists or dental hygienists (n = 2, 4 %) and one nurse assistant (2 %).

Eighty-five percent (n = 99) of the responders (patients, family members and clinicians) reported that their overall impression of the care diary was good or very good. Sixty eight per cent of the clinicians (n = 32) believed that the diaries were useful for their patients, but only 38 % (n = 18) thought that the diaries could be useful for the patients' family.

A majority of the patients and family members (n = 56, 80 %) stated that they always read the notes in the care diaries from clinicians, but only 21 % (n = 15) believed that the clinicians always read their notes. Only 12 (26 %) of the clinicians reported that they always read, and 12 (26 %) that they sometimes read the notes from the patients in the diaries.

Patients and family members reported difficulties with the care diaries, mainly in comments expressing frustration that the clinicians did not seem interested in the care diary. Clinicians reported difficulties such as lack of time to write both in diaries and nursing files. The calendar with appointments and the list of telephone numbers was reported as the most useful sections of the diaries, from patients, family members and clinicians. Three patients (7 %), two family members (7 %) and three clinicians (6 %) did not find any use of the care diary.

The results also gave several suggestions for improvements, mainly concerning layout and content of the care diaries.

6.2 PAPER II (THERMOPLASTIC FACE MASKS)

A total of 260 H&N cancer patients were included, and 241 (93 %) were evaluated. There were no significant differences between the groups in terms of age, gender, tumour stage, type of treatment or type of skin. We found no statistically significant differences between the groups (HM or HSM) in terms of reproducibility (measured in reported set-up errors and required field shifts). A field shift that was considered to be related to the immobilization system was requested in 10 % of the patients (either after first treatment or during the fourth treatment week). Patients using HSM experienced significantly more claustrophobia (p = 0.023). There were no statistically significant differences between the HM and HSM as to how the patients experienced pain, the fit of the mask, discomfort or the possibility to move the head within the mask during treatment. Patients allocated to HSM receiving ≥ 60 Gy were found to have more radiation skin reactions (WHO grade 1, 2 and 3).

6.3 PAPER III (SMOKING CESSATION, QUALITATIVE STUDY)

The data consist of descriptions of experiences of the smoking cessation program from 13 H&N cancer patients (nine men and four women). Ten of the patients reported active or previous substance abuse (other than nicotine). Nine of the patients stopped smoking during the study. Two patients quit for a short period and then continued smoking, and two patients continued to smoke during the study. All 13 patients were asked to keep a diary, but only six completed this to an extent sufficient for analysis. Data also consist of diary notes from two RT nurses involved in the smoking cessation program. The nurses' diary notes relate to all 13 patients.

The results from this qualitative study are presented in three major categories: the patient-nurse relationship, factors facilitating or hindering behavioural change, and drug (ab)use. The most important finding of this study is the importance of a therapeutic patient-nurse relationship for the smoking cessation process, which was recognized in both patient and nurse diaries. The nurses describe how this close relationship helped them integrate smoking cessation into standard cancer care and that this closeness helped them sense when the patient was receptive for smoking cessation advice and support. Factors reported as facilitating or hindering behavioural change included the nature of smoking as a comprehensive problem, readiness to change behaviour, motivation and contextual matters. The third category, drug (ab)use, describes the behavioural change process and different aspects on nicotine addiction.

6.4 PAPER IV (SMOKING CESSATION, QUANTITATIVE STUDY)

The sample consists of 50 H&N cancer patients, who were active smokers at the first visit to the RT unit. Most of the patients were male ($n = 41$, 82 %) and the median age was 62 years. More than half of the patients had advanced disease (clinical stage III-IV) at diagnosis and 40 % ($n = 20$) lived alone. The RT doses varied from 50 – 68 Gy. The level of nicotine dependence, according to FTND was medium (median 6). The levels of CO in expired air at baseline ranged from 7-28 ppm. Thirty patients (60 %) reported other types of substance abuse, predominantly alcohol.

Thirty-seven patients (74 %) were tested smoke-free weekly during the RT-period and of the 41 patients alive at the one-year follow-up, 21 (51 %) were reported and tested smoke free at all test occasions during the first year. At the one-year follow-up visit, 28 patients (68 %) were tested smoke-free. Most patients ($n = 46$, 92 %) used ANP during the first year 60 % ($n = 30$). The nicotine products were used in all kind of combinations and six patients used all available products during the first weeks of the smoking cessation period. The most commonly used ANP was nicotine patches ($n = 42$, 89 %) and a majority of patients combined the patches with other nicotine product/s (Table 2 in paper IV). Ten patients (24 %) used ANP at the one-year follow-up visit. Of these patients, one used patches only, five patients used snus only, one patient used gums only and three patients used a combination of two or three ANP.

7 GENERAL DISCUSSION AND CONCLUSIONS

7.1 PAPER I (CARE DIARIES)

Even if this study has several limitations, such as small sample size and a lack of validated test instruments, the results indicate that care diaries may be useful tools in communicating with H&N cancer patients and their families. This evaluation gave us an insight on how the diaries were used and experienced both by H&N cancer patients, family members and also clinicians in different care settings.

One of the difficulties reported by some patients (and also confirmed by the clinicians) in this study was that only a minority of the clinicians always read the patients and family members notes in the diaries. This was also found in another study on ‘logbooks’ for H&N cancer patients by van Wersch et al [64]. Some patients in our study also commented on this issue, and expressed that this lack of involvement from some clinicians made the diary less useful.

Conflicting results from earlier studies on care diaries may be a result of different needs for different groups of patients and also differences between individual patients. The differences could also be contextual.

One of the possible benefits with the care diaries is that they allow patients and families to choose their level of involvement. Some patients used the diaries solely as a time planner, while others took a more active role regarding pain management, oral care, nutrition and other issues. Thomas et al. [59] also found that ‘take home’ material enables the patients to share information with their families and thereby facilitate support, which was also described by some of the family members in this present study.

The diaries have been improved considerably since this study was performed. We received valuable information on how to improve the care diaries, could identify areas in need of improvement such as the importance of repeated information to clinicians, and especially in palliative care settings. Much of the improvements were taken directly from the suggestions given in this evaluation. Care diaries have now also been developed for patients with lung cancer and an evaluation including both qualitative and quantitative data is on going. Information may also change over time so the evaluation of new approaches, such as care diaries, should in my opinion be ongoing and adapted to new conditions. The conflicting research concerning information and education to cancer patients probably indicates that there is no one golden standard on how to address these issues. An individual approach, allowing for several options of information, involvement, self-care and focusing on the individual H&N cancer patients’ and his/her families needs are probably best practice.

7.1.1 Methodological considerations

One strength with this present study was that patients, family members and clinicians’ experiences were included, which gave different perspectives. As mentioned, a validated test instrument would have been useful but was not found for the purpose of this study. A strength of the care diaries was that the content was developed from experiences by H&N cancer patients in a earlier qualitative study [142].

This was a relatively small sample of patients, family members and clinicians. However, a relatively early evaluation (and thereby not yet used by large number of patients) was believed to be important to be able to improve this new approach. A design with mixed method, including qualitative data and analysis would have given a deeper understanding, especially since the frequent comments received in the questionnaires were quite extensive from patients, family members and clinicians indicated that they “had a lot to say”.

7.2 PAPER II (THERMOPLASTIC FACE MASKS)

We found no significant differences in reproducibility between the HM and the HSM. Both types of masks (HM and HSM) were associated with a reproducibility that did not require field shifts for 90 % of the patients. It is difficult to compare the results from this study to other studies since, study design, immobilization and RT techniques often differs.

Claustrophobia was found to be a bigger problem than expected both when the HM and the HSM was used. The use of HSM was associated with significantly more frequent claustrophobia (58%), compared with for the patients using the HM (45 %) ($p = 0.033$). I believe that claustrophobia caused by the immobilization devices during RT is an underestimated problem among clinicians. Roques et al. [143] expressed criticism in an editorial comment regarding this present study and were of the opinion that if only you have experienced RT technicians, claustrophobia was not an issue. However, all patients (both patients using HM and HSM) in our study were treated by the same RT nurses, with long experience, and still a significant difference in claustrophobia was detected between the groups.

We found only one published paper aiming at claustrophobia for H&N cancer patients undergoing RT. Kim et al. [144] compared in a small study ($n = 8$) two types of immobilization systems, one of which were specifically aimed for claustrophobic patients. However, no subjective data on the patients’ experiences of claustrophobia was collected. Some H&N cancer patients are describing in a qualitative study by Rose and Yates [21] that having to wear the mask was the worst part of their illness. My clinical impression is that it might cause extra pressure on the H&N cancer patient to know that they need the cope with the mask to receive the treatment in a safe way. On the other hand if the patient is being carefully informed of the purpose of the mask and are being encouraged to be actively involved in the moulding process, they might cope better with the procedure. New RT techniques, such as IMRT may be more time consuming, resulting in ever longer time for the patient in the mask. The issue of claustrophobia might therefore be even more important to address.

Radiation skin reactions were found to be significantly more associated with the use of HSM. Both erythema, dry and moist desquamation (WHO grade 1, 2 and 3) was found more among patients using the HSM, receiving RT doses ≥ 60 Gy. This is an important finding, since severe skin reaction may lead to treatment interruptions.

Our conclusion is that the shorter HM should, if possible, be used for patients receiving RT doses ≥ 60 Gy to reduce the risk of severe side effects such as skin reactions and claustrophobia.

7.2.1 Methodological considerations

This study has several strengths, such as large sample size, randomised groups, and field shifts done according to a strict protocol. Another strength of this study was that a RT nurse and an oncologist, blinded to what type of mask being used, performed the skin assessments jointly. This was considered especially important, since there were different options among the staff prior to this study on which type of mask they preferred.

One limitation was that only two sets of port films were taken and compared during each patient's treatment period. There are of course possible that errors in the reproducibility occurred at other occasions during treatment and therefore never found in this study. However, the RT nurses also assessed the set-up reproducibility and shifts as small as 1 mm or more were recorded. These assessments were performed weekly and any major instability or other major set-up error would probably be detected.

Claustrophobia was reported more frequently than expected. A baseline assessment of earlier experiences of claustrophobia and psychosocial status (baseline and follow-up) could have been given important information on the impact of claustrophobia during RT.

Another limitation was that the port films were assessed and compared manually. Digital images may have been a more sophisticated and objective way of comparing the films and also might have allowed for a more detailed comparison, were differences at certain anatomical sites may have been found. However, digital image technique was not available at our department at the time for the study. This study, in my opinion, is large enough sample to detect any clinical relevant differences in the reproducibility between the two types of masks. Required shifts were also performed after a detailed protocol, to reduce the risk for different assessments from different oncologists.

The WHO scale for acute and late toxicity, which was used in this study, has been criticised for the fact that it was first developed for chemotherapy induced toxicity and that it does not incorporate the wide range of radiation reactions. However, we found it accurate and relatively easy to implement due to earlier experience among the staff and the fact that this scale were scoring all erythema, regardless of the intensity as grade 1. My clinical impression is that erythema could be difficult to grade due to interpersonal discrepancies, different skin types and lighting in the assessment room etc. In my experience, the intensity of the erythema does not necessarily have to be related to intensity of pain or other symptoms, whereas dry or moist desquamation much more seems to be related to severe pain, risk for infections and are also more distinguished and therefore easier to assess.

7.3 PAPER III (SMOKING CESSATION, QUALITATIVE STUDY)

The purpose of this study was to gain knowledge on H&N cancer patients' and their nurses' subjective experiences of the smoking cessation process. The results complement prior knowledge and the objective evaluation of the smoking cessation program presented in paper IV.

One important finding was the potential value of a therapeutic patient-nurse relationship on the smoking cessation process, which is not described in the literature on smoking cessation in cancer patients in general. Therapeutic nursing has been defined by McMahon and Pearson as “nursing that deliberately leads to beneficial outcomes for the patients” (p 7). McMahon and Pearson also describe activities included in therapeutic nursing as: The patient-nurse relationship, the practise of conventional nursing interventions, complementary therapies and patient teaching. The patient-nurse relationship is described as a therapeutic process involving the three following elements; partnership, intimacy and reciprocity. Partnership is now also a legal right in Sweden and patients have the right to be involved in decision-making regarding their own care. McMahon and Pearson [145] describes intimacy as an interpersonal closeness between the patient and the nurse and reciprocity as the patient-nurse relationship is beneficial and necessary for both the patient and the nurse. All three components were found in the data, both from patients and nurses.

From a professional perspective, therapeutic nursing according to McMahon and Pearson means that the nurses identified and prioritised their patients’ problems in partnership with the patient, with the goal of self-care. This is evidenced clearly in the diaries. McMahon and Pearson also points out that it is critical that nurses recognize that they have the ability and authority to intervene positively to solve the patient’s problems, but this recognition is not as clearly evidenced in the empirical data.

As described previously, many H&N cancer patients live socially isolated [146]. These patients might need extra support and the nurses’ primary task is to try to create a therapeutic relationship with the patient, built on respect and trust. Continuity and availability is essential to create this kind of relationship, and can be a challenge when a large number of clinicians in the multidisciplinary team are involved. To create a relationship is an important base to build information and education on and the nurses’ tool to coach the patients through the continuum of care. A non-judgemental approach, in my experience, is essential though many of these patients have negative previous experiences from the health care system, which might have caused more blame or guilt to the patients’ life style. In interventions for behaviour change, such as smoking cessation program, therapeutic nursing appears to be a useful approach, since reciprocity and partnership have been described as important issues in e.g. Motivational Interviewing [123]. The results also show that cancer nurses may have the opportunity to successfully integrate smoking cessation into standard cancer care.

7.3.1 Methodological considerations

Although diaries were useful in gaining insight into patients’ and nurses’ subjective experiences on the smoking cessation process, only a limited sample of patients kept diary notes for any extensive periods. However, we found the data to be robust and provide a strong foundation for analysis. The data from the nurses complemented the data from the patients and gave different perspectives to the smoking cessation process.

The involvement of the author in the study can be discussed. Although I also kept diary notes in my role as clinical nurse, they were excluded from the study to reduce the risk of potential bias. The close involvement gave me insight and deeper understanding into the process involved for the participants.

The Framework approach gave clear structure to the analytic process and also allowed evidence from earlier literature to be incorporated with new empirical findings in a systematic manner. However, there is a risk that the strict procedures become too elaborate, which might disturb the interpretations.

Models for behaviour change are a part of our smoking cessation program and data both from patients and nurses confirms how these models were included in the program. The nurses report that the models gave structure to their consultations with the patients and some patients describe how the nurses had a non-judgemental attitude towards smoking. This is in line with suggestions from, e.g. The Trans Theoretical Model of Change and Motivational Interviewing [123, 129].

7.4 PAPER IV (SMOKING CESSATION, QUANTITATIVE STUDY)

The quit rates in this current study was relatively high, in comparison to other smoking cessation studies on cancer patients [116, 147, 148]. The results indicate that even H&N cancer patients with heavy nicotine addiction and multi-drug abuse can quit smoking successfully with structured support, indicating that cancer could be a “teachable moment” for patients with H&N cancer. This is in line with the results from a previous randomised study, on physician delivered smoking cessation by Gritz et al. [130], which showed that 64 % of the H&N cancer patients (in the intervention group) were tested smoke-free at one year follow-up.

Even if Rice and Stead [120] concluded in their Cochrane review on nursing interventions for smoking cessation that intense interventions were no more effective than less intense intervention, there might be special conditions for this group of patients. Many H&N cancer patients have several characteristics that may make quitting smoking difficult (heavy nicotine addiction, multi-drug abuses and social isolation) and smoking cessation may be of great importance for the outcome of the cancer treatment.

In our smoking cessation program the aim is to improve the rates of smoke free patients, rather than nicotine free patients. To treat nicotine addiction, e.g. quit using nicotine, for H&N cancer patients could be very difficult. To be diagnosed with a life threatening disease may be extremely stressful and many H&N cancer patients also have a strong nicotine addiction. Our program therefore includes providing the patients with ANP, free of charge for the first ten weeks. These products are often referred to as NRT (nicotine replacement therapy). These products all include nicotine, which makes the term problematic. The term alternative nicotine products (ANP) are more appropriate, in my opinion.

To use snus in smoking cessation program may be controversial. To replace a tobacco product with another tobacco product have been criticised by Bask and Melkerson [149] but their conclusions have on the other hand been questioned by Ault et al. [150]. The alternative for H&N cancer patients with a heavy nicotine addiction is most probably continuing smoking and since several researchers have failed to find any serious adverse effects on snus [11, 106, 107, 151] we believe that snus is a better alternative. Only five of the patients in this study used snus at the one year follow-up. This indicates that only a small number of patients replace cigarettes with another type of tobacco (snus). Most patients used snus and other ANP during the cessation period and then stopped using nicotine.

Many patients in this study used ANP for longer periods and also in higher doses than recommended by the producers, but most patients quit using ANP during the follow-up period (one year). The products were only cost-free for the patients during the first ten weeks. After this period the patients decided to either continue using and buying ANP or to stop using the products. Several researchers [102, 127, 128] conclude that higher doses of ANP, than generally recommended, might be beneficial for patients with strong nicotine addiction or multi-drug abuse.

Only a few patients in the study used nicotine gums. There were indications that gums were difficult to use for some patients, due to poor teeth and /or side effects such as oral mucositis. Nicotine gums may therefore be contraindicated to patients with oral problems or when the oral cavity is being irradiated.

It is possible that more patients would have been able to quit smoking in the present study if pharmacologic treatment (e.g. Bupropion) was included as an option, especially for patients with depressive symptoms.

7.4.1 Methodological considerations

There are several limitations to this study, such as a small sample, no control group, but also strengths such as verifications (CO tests in expired air) of self reported smoking status and a follow-up of one year. There is also a possibility that some patients' felt obligated to participate in the study, to please the treating staff. However the high quit rates remained high after RT, when the contact with the staff was less intense, which indicate a sincere interest to be smoke free among the patients.

7.5 GENERAL CONCLUSIONS

I conclude that care diaries may be beneficial and meet some of the H&N cancer patients need of individual information, involvement, self-care and communication, and thereby improve the dialog between the patients, families and clinicians, but more sophisticated evaluations on larger groups of patients are needed.

There is no significant difference in reproducibility when comparing two types (HM and HSM from Posicast[®]) of thermoplastic face mask for immobilization during H&N RT. The smaller HM reduced feelings of claustrophobia, as well as radiation skin reactions, for patients receiving ≥ 60 Gy. The smaller mask did not compromise the reproducibility of the set-up. An individual approach is therefore recommended, with the shorter HM as the first choice, especially for patients receiving ≥ 60 Gy and/or with previous experiences of claustrophobia.

Even H&N cancer patients with several risk factors such as heavy nicotine addiction, social isolation, multi-drug abuse, can quit smoking successfully with the systematic support given in our smoking cessation program. H&N cancer can be a "Teachable moment" and many H&N cancer patients are interested in quitting smoking, if support is provided and integrated into standard cancer care. The nurse-patient relationship can be an important therapeutic tool in the smoking cessation process for H&N cancer patients. The nurse-led smoking cessation program needs to be tested on larger samples with appropriate control groups.

8 ACKNOWLEDGEMENTS

This thesis would not have been possible without the incredible support and generosity I have received from my family, colleagues, supervisors, friends and of course from my biggest source of inspiration, all of the H&N cancer patients and their families who have shared their thoughts and life time stories with me. I would like to direct special thanks here to some people, who have been central in helping me with this thesis.

My supervisors, Freddi Lewin and Lars Erik Rutqvist, for all their incredible support and encouraging. Special thanks to Freddi for believing so much in me and always giving me support. Also thanks for all the interesting clinical and scientific discussions and for describing and practicing the term “Onco-tourism” with me. Special thanks to Lars Erik for sharing your wisdom and helping me think straight, in times of confusion (there has been a few).

My very dear and good friends (and colleagues), Ing-Marie Moegelin, my “sister in beam” and the unofficial chairman of my fan club and Ann-Sofi Hörjel, for always being honest and giving me the best support possible. Both of you have shown so much generosity and through the years we have shared so many laughs (and tears). I can honestly say that without the two of you this thesis would not have happened.

Carol Tishelman, my co-author, friend and fantastic role model. Great thanks for all your time, generosity and engagement, always available with instant feedback and enormous knowledge. I am very grateful for the way you have helped me to clarify and develop my thoughts.

“My” nursing staff, (Britt-Marie, Barbro, Karin G, Pilar, Karin L, Madde, Jane, Magnus, Ylva, Anna, Nina, Håkan, Annakaisa, Micke, Gunnel, Susanne, Larissa, Ann, Lena, Martina, Nadja, Sakarias and Anne-May) for putting up with all my ideas and for being so involved and dedicated in all my research. You are the best!

Britt-Marie Bernardsson, Helena Leveälathi, Göran Laurell, Magnus Lagerlund, Ylva Tiblom-Ehrsson, Maud Ek, Katja Markovic, Helena Sjödin, Christer Svensson, Berit Wennberg, Ansi Gerhardsson, Jan Lundgren, Therese Engström, Polymnia Nikolaidis, Ylva Orrevall, Helena Lundgren, Kicki Finnilä for great collaboration both in clinical and in research work.

Hemming Johansson for necessary and highly professional help with statistics but also for interesting conversations and many laughs.

Inga-Britt Pettersson, for great help with all kind of administrative and economical issues.

Sarah Kagan, my dear friend and role model, who taught me that clinical practice and cancer nursing research, is possible to combine but also a great challenge. Special thanks for all your feedback and support; wherever you have been in the world you have always taken your time to reply to hundreds of my emails.

Peter Ceder, my boss, who gave me the chance to lead the best RT nursing team in the world and also the opportunity to combine research time with clinical practice, even in times of heavy clinical workload and major reorganisations.

Karl Olof Fagerström, co - author and “smoking cessation guru” who helped me develop and implement our smoking cessation program and also supporting the nurses involved.

David Payne, my co-author in paper II, who gave extremely valuable help and assistant both in person and via e-mail.

My dear daughters, Ellinor and Amanda. The love of my life! Thanks for keeping me down to earth and remembering what life is really about. Also thanks for practical helps, such as making new care diaries (Amanda) and for all kind of administration tasks (Ellinor).

My husband, Jim, who have showed an incredible understanding and support during all the years. Special thanks for all the help with the English language and also for being my personal photographer.

My parents, for always believing in me and teaching me that everything are possible.

Last but not least, thanks to Daniel, who is no longer with us, and his parents, Britt-Marie and Yngve, who taught me what cancer nursing is really about and that the relationship between a patient, family and nurse could be extremely important for both parts.

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