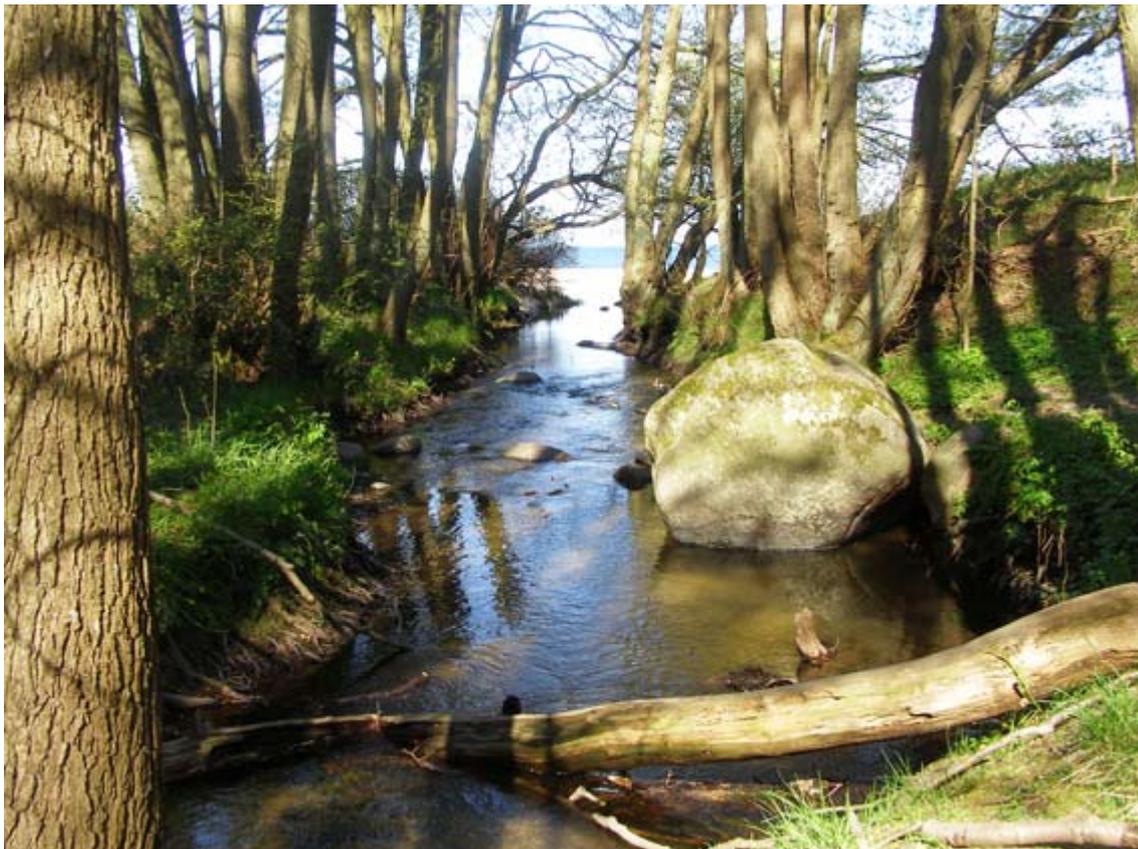


Doctoral Thesis – Nordic School of Public Health, Göteborg, Sweden 2010

# **LIVING WITH HEAD AND NECK CANCER: A HEALTH PROMOTION PERSPECTIVE**

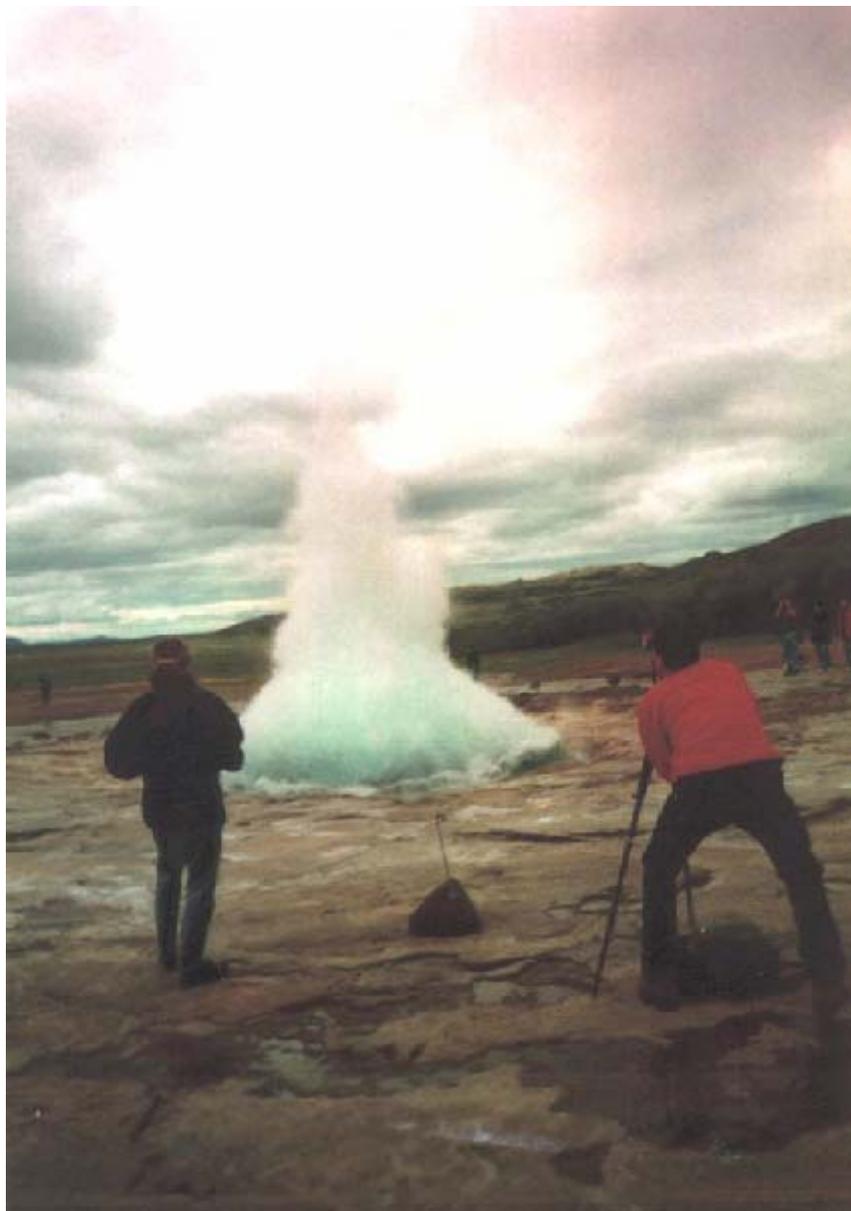
**– A Qualitative Study**



**Margareth Björklund**



**LIVING WITH HEAD AND NECK CANCER: A HEALTH  
PROMOTION PERSPECTIVE – A Qualitative Study**  
Margereth Björklund



**Being close to nature works wonders with the soul (Tomas Sjödin)**

Doctoral Thesis – Nordic School of Public Health, Göteborg, Sweden 2010

**LIVING WITH HEAD AND NECK CANCER: A HEALTH  
PROMOTION PERSPECTIVE – A Qualitative Study**

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and Gunnar S. The artist Gunvor Johansson painted the portrait.

## ABSTRACT

**Background and aim:** In society there is a growing awareness that a vital factor for patients with chronic diseases, such as head and neck cancer (HNC), is how well they are able to function in their everyday lives – a common, but often overlooked, public health issue. The overall aim of this thesis is to reach a deeper understanding of living with HNC and to identify the experiences that patients felt promoted their health and well-being. It also explores the patients' experiences of contact and care from health professionals and whether these encounters could increase their feelings of health and well-being; salutogenic approach.

**Methods:** This thesis engages a qualitative data design. On three occasions, 35 purposively selected patients were interviewed (31 from Sweden and one from Denmark, Finland, Island, and Norway). The first study was conducted in the Nordic counties (**I**), and the remaining studies were conducted in Sweden (**II, III, IV**). Interviews were performed on a single basis (**I, II, III**) and then repeated (**IV**). The individual, semi-structured qualitative interviews used open-ended questions (n=53). Three different forms of analyses were used: critical incident technique (**I**), thematic content analysis (**II**), latent content analysis (**III**), and interpretative descriptive analysis (paper **IV**).

**Findings:** Living with head and neck cancer was expressed as living in captivity, in the sense that patients' sometimes life-threatening symptoms were constant reminders of the disease. The patients experienced a threat against identity and existence. Patients struggled to find power and control over everyday life, and if successful this appeared to offer them better health and well-being along with spiritual growth. The general understanding was that these patients had strong beliefs in the future despite living on a virtual rollercoaster. The patients went through a process of interplay of internal and external enabling that helped them acquire strength and feelings of better health and well-being. Consequently, they found power and control from inner strength and other health resources, e.g. social networks, nature, hobbies, activity, and health professionals. However, the findings also revealed the opposite; that some patients were more vulnerable and felt powerless and faced everyday life with emotional and existential loneliness. They were dependent on next of kin and health professionals. Having good interpersonal relationships and emotional support 24 hours a day from next of kin were crucial, as were health promoting contacts and care from health professionals. This health promoting contact and care built on working relationships with competent health professionals that were available, engaged, respectful, validating, and, above all experienced in the treatment phase. But many patients experienced not health promoting contact and care – and a sense of not being respected, or even believed. Added were the patients' experiences of inadequate coordination between phases of their lengthy illness trajectory. They felt lost and abandoned by health services, especially before and after treatment.

**Conclusions:** Inner strength, good relationships with next of kin, nature, hobbies, and activities could create strength and a sense of better health and well-being. Patients experienced a mutual working relationship during dialoguing and sensed co-operation and equality in encounters with competent health professionals. This could lead to enhanced power and control i.e. empowerment in a patient's everyday life. The findings highlight psychosocial rehabilitation in a patient-centred organisation when health professionals support patients' inner strength and health resources, and also offer long-term support to next of kin. Finally, this research suggests that if health professionals could gain a deeper understanding of the psychosocial, existential, social, and economic questions on patients' minds, they could better sense how patients feel and would be better equipped not only to offer greater support, but to raise their voices to improve health policy and health care for these patients.

**Key words:** Head and neck cancer, public health, health promotion, empowerment, qualitative methods, everyday living, nursing. **Doctoral Thesis – Nordic School of Public Health, Box 12133, SE-4022 Göteborg 2010.** E-Mail: margereth.bjorklund@hkr.se

## SVENSK SAMMANFATTNING

**Syfte och bakgrund:** Avhandlingens övergripande syfte var att få en djupare förståelse för personer med huvud – halscancer vardagsliv samt vad som främjar deras hälsa och välbefinnande dvs ett salutogent synsätt. Kroniska sjukdomstillstånd såsom cancer räknas numera till de stora folksjukdomarna och vid huvud – halscancer är vikten av ett fungerande vardagsliv emellertid ett ofta förbisett folkhälsoproblem.

**Metod:** Avhandlingen omfattar fyra delarbeten baserade på kvalitativa data. Resultaten baseras på semistrukturerade individuella intervjuer (n=53) som riktades till 35 utvalda personer. Den första studien (**I**) genomfördes i Danmark, Finland, Island, Norge och Sverige och de övriga i Sverige (**II, III, IV**). Intervjuerna genomfördes vid ett tillfälle (**I, II, III**) och vid upprepade tillfälle (**IV**). Tre olika textanalyser användes, kritisk händelse teknik (**I**), tematisk innehålls analys (**II**), latent innehållsanalys (**III**) och tolkande beskrivande analys (**IV**).

**Resultat:** Att leva med huvud - halscancer beskrevs som ett liv i fångenskap och upplevdes som att åka i berg och dalbana mellan hopp och förtvivlan. De ofta livshotande symtomen påminde ständigt om sjukdomen och upplevdes som hot både mot existensen och mot identiteten. Detta till trots kom ibland en stark optimism och tro på framtiden till uttryck. Några av de intervjuades vardagsliv präglades dock av känslomässig och existentiell ensamhet och upplevelser av sårbarhet och maktlöshet. Att ha makt och kontroll över den egna livssituationen liksom närståendes känslomässiga stöd, ibland dygnet runt, främjade hälsan. Hälsofrämjande kontakter med vårdpersonalen upplevdes främst under sjukhus vistelsen. Avgörande var en god och bekräftande patient vårdar relation samt att personalen hade hög kompetens och visade engagemang och respekt i vårdsituationen. Flera av de intervjuade beskrev dock allvarliga brister i kontakten med sjukvården. Upplevelser av brist på respekt och att inte bli trodd i sin sjukdomsupplevelse beskrevs, vilket vanligast i perioderna före och efter sjukhusvistelsen. Samordningen mellan hälso- och sjukvårdens olika funktioner upplevdes som bristfällig under hela sjukdomsförloppet.

**Konklusion** Inre styrka, goda relationer med närstående, nära kontakt med naturen, hobbyer och andra aktiviteter skapade upplevelser av hälsa och välbefinnande hos personer med huvud - halscancer. I dialog med kompetent vårdpersonal, där samverkan och jämlikhet var tydlig, upplevdes ömsesidiga, vänliga relationer som en hjälp för dem att få ökad egenmakt och kontroll i vardagslivet. Resultatet visar på patienternas långvariga kamp med ett vardagsliv med ständig känslomässig, psykosocial, existentiell, social och ekonomisk oro. Resultatet pekar också på en brist på patientcentrerad organisation och psykosocial rehabilitering, där vårdpersonal stödjer patienters inre styrka och hälsoresurser. Förhoppningen är att resultatet kan leda till en ökad förståelse hos vårdpersonal för hur vardagslivet kan upplevas då man har en huvud- hals cancer, för att på så vis ge adekvat hjälp till dessa patienter och deras närstående.

**Nyckelord:** Huvud - halscancer, folkhälsa, hälsofrämjande, egenmakt, kvalitativa metoder, levda erfarenheter, omvårdnad.

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## ORIGINAL PAPERS

This thesis for the degree of doctor in public health is based on the following papers, referred to in the text by their Roman numerals:

- I Björklund M, Fridlund B. (1999). Cancer patients' experiences of nurses' behaviour and health promotion activities: a critical incident analysis. *European Journal of Cancer Care*, 8 (4), 204-212.
- II Björklund M, Sarvimäki A, Berg A. (2009). Health promoting contacts as encountered by individuals with head and neck cancer. *Journal of Nursing and Healthcare of Chronic Illness*, 1 (3), 261-268.
- III Björklund M, Sarvimäki A, Berg A. (2008). Health promotion and empowerment from the perspective of individuals living with head and neck cancer. *European Journal of Oncology Nursing*, 12 (1), 26-34.
- IV Björklund M, Sarvimäki A, Berg A. (2010). Living with head and neck cancer: a profile of captivity. *Journal of Nursing and Healthcare of Chronic Illness*, 2 (1), 22-31.

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## **ABBREVIATIONS & ACRONYMS**

HNC	-Head and Neck Cancer
NHPH	-International Network of Health Promoting Hospitals
IOM	-Institute of Medicine
LU	-Lund University
SSF	-Swedish Nurses Association
NCCDPHP	-National Center for Chronic Disease Prevention and Health Promotion
NIPH	-National Institute of Public Health, Sweden
NNF	-Northern Nurses Federation
NPH	-Nordic Public Health
SBU	-Swedish Council on Technology Assessment in Health Care
SWEDPOS	-Swedish Society for Psychosocial Oncology
WMA	-World Medical Association
WHO	-World Health Organization

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# Preamble

Through my former work as registered nurse in an ear, nose, and throat clinic I met many patients who faced a mix of challenges from head and neck cancer (HNC) tumour growth and the side effects of treatment. With help of medication, treatment, health resources, and other solutions they regularly, after a time, felt better and looked ahead. I was impressed by the patients' willpower to look forward despite their unfolding ill health and its accompanying problems, e.g. breathing, eating, bleeding, and speaking complications. This sparked my interest and curiosity to learn and understand more about the implications of living with HNC and to identify the experiences that patients felt promoted their health and well-being when captured in this vulnerable life situation. This quote is from a woman aged 55, narrating her experience of being in a vulnerable situation during hospitalization with valuable health professionals' encounters:

If you give a person...unexpected attention, I think you save a lot of work... for yourself and in answering many questions from patients...just say, 'I have a few minutes and thought I would spend them with you'...it's the easiest way to reach people...yes, I think they neglect the person in health care, and that's deadly...

# Introduction

This thesis aims to reach a deeper understanding of living with HNC and to identify the experiences that patients felt promoted their health and well-being. Furthermore, it conveys the patients' experiences of care and contact with health professionals, and examines whether these encounters could increase patients' feelings of better health and well-being. The intent has been to place this area under discussion in the sphere of public health and health promotion since an increasing number of people are now living with chronic HNC (Parkin et al., 2005; Syrigos et al., 2008). Hence, the implications are a heavy illness burden for patients and their next of kin and a continuing need for access to services and support from health care and society.

# Background

## Public health and head and neck cancer

All definitions of public health share a common aim, i.e. to reduce disease and maintain health (Beaglehole & Bonita, 2001). Public health, in addition to addressing the efficacy of health and medical care is an interdisciplinary area involving social structure, working life, environment, and the care system serving the population's health (ibid.). In the nineteenth century public health (i.e. the old public health approach), sought changes in the physical environment and point at e.g. education of personal hygiene, and development of social standard of living sufficient for preservation of health, additional infection control, medical and nursing services for early diagnosis and preventive treatment of disease (ibid).

In the mid 1970s, the movement towards a new public health approach pursued changes in economic, political, social, and environmental conditions believed to enhance health. This new public health approach emphasises the collective responsibility for health while protecting and promoting the public's health, with attention to partnership, prevention, and a multidisciplinary basis for action. The topics are causal, socioeconomic determinants of health and disease, in addition to more proximal risk factors. These determinants of health – i.e. our life circumstances linked not only to living with illness, genetic disorders, or other disease, are linked also to income, educational status, and not least to social relationship with others (ibid.). All of these factors seem to motivate connecting public health research to individuals and groups living with HNC. Further, it is not uncommon that the location of the tumour and the side effects of treatment (surgery and radiation) often result in permanent, visible disfigurement, and those affected could experience this as a social disability (Vickery et al., 2003). Visible disfigurement is known to be associated with extensive psychosocial difficulties, considering the face is the initial focus in encounters and central to verbal and non-verbal communication (Rumsey et al., 2004). This inconvenience could be amplified since society attaches tremendous importance to physical attractiveness, and visible deformity, particularly of the face and neck, can be difficult to disguise (Feber, 2000). Dropkin (1999) points out that even a brief glimpse of the affected person informs the viewer of a difference from standard appearance. Additionally, these individuals often have poor speech and might avoid social contact, often restricting them to a close circle of friends and relatives (Rumsey et al., 2004).

In Sweden, the National Institute of Public Health (NIPH, 2003) has stipulated specific objectives for public health by highlighting people's participation and influence in health care and society. These objectives correspond to those in other Nordic countries as regards principles guiding public health towards more health promoting health and medical care (Nordic Public Health [NPH], 2009). There is also general agreement on strategies, e.g. regarding the public's economic and social security, healthier working life, improved physical activity, reduced use of tobacco and alcohol, safe environments, good eating habits, and safe food products (NIPH, 2003). When an individual contracts an HNC disease he/she always shoulders the primary responsibility for personal health. If he/she is too sick, the responsibility shifts to the next of kin. Finally, the responsibility shifts to society. On the individual level, public health aims to promote health and enhance comfort for those groups and individuals that are most vulnerable to ill health (cf. Krantz, 2002). Patients with HNC search for relief and health resources when they experience long-lasting feelings of ill health (cf. Bjordal et al., 2001). However, it appears to be problematic for them to achieve better health and well-being since they live constantly with chronic problems, e.g. eating and swallowing disorders that accompany their increasing age.

## Head and neck cancer

HNC is comprised mainly of squamous cell and adenocarcinoma and includes cancer of the lip, tongue, salivary gland, mouth, pharynx, oropharynx, nasopharynx, hypopharynx, nose, sinuses, thyroid, ear, and larynx (Anniko, 2006). HNC is most common in people aged >50 years, and the percentage of elderly patients is rising due to the increasing lifespan (Syrigos et al., 2008). HNC presents different aetiologies and pathology, but tobacco and alcohol use, particularly in combination, are known risk factors (Talmi, 2002). The pattern of HNC is not the same for both sexes, e.g. women have a three to four time greater chance for thyroid cancer than men have (Lope et al., 2005). In contrast, cancer incidence in the tonsils has increased threefold in men since the 1970s (Gillison, 2008). Some authors judge these results as an indication of an epidemic of virus-induced carcinoma, since nearly all tonsil cancer originates from a human papilloma virus infection of the mucosa (Näsman et al., 2009; Andrews et al., 2009).

HNC is the fifth most common cancer in the Nordic countries. The annual incidence (i.e. new cases) of this cancer is increasing, and its prevalence reflects a long-term survival rate (Parkin et al., 2005). However, the incidence of HNC varies amongst the Nordic countries, representing from 1.5% to 5% of all malignant tumours, i.e. around 4500 individuals receive this diagnosis annually (Parkin et al., 2005). Table 1 presents an overview of the annual incidence during 2007 and the prevalence of HNC in the Nordic countries.

The reported total prevalence is not recognised as the most appropriate figure since many of the patients are cured and not included as a cancer patient by the health services. For that reason, 5-year prevalence is also described. In total, 50% of the patients survive 5 years following diagnosis. This is a high survival rate compared to other cancer diseases (Parkin et al., 2005). Yet the 5-year survival rate could vary from 50% to 90%, depending on tumour location, size, and stage (Anniko, 2006). The survival rate has increased in recent decades due to the many advances in surgery and developments in combining radiation therapy and chemotherapy (Zackrisson et al., 2003; Caglar & Allen, 2007; Jackson et al., 2009). These findings correspond to other cancer research showing that advancements in cancer research have reduced the risk of cancer death across the life span. Therefore, cancer should be recognised as a chronic illness (Kort et al., 2009).

Table 1 Overview of annual incidence (i.e. new cases) and prevalence of HNC in the Nordic countries

	Incid ence 2007	Men	Women	Total preval ence	Men	Women	5-year preval ence	Men	Women
Denmark <sup>1)</sup> (Population 5.5 million)	n= 823	n= 553	n= 270	n= 10 094	n= 5914	n= 4180	n= 8930	n= 5381	n= 3549
Finland <sup>2)</sup> (Population 5.3 million)	n= 1432	n= 831	n= 601	n= 15 048	n= 7545	n= 7503	n= 5464	n= 2711	n= 2753
Iceland <sup>3)</sup> (Population 0.3 million)	n= 46	n= 19	n= 27	n= 636	n= 194	n= 442	n= 570 both sexes		
Norway <sup>4)</sup> (Population 4.7 million)	n= 1259	n= 731	n= 528	n= 12 362 both sexes			n= 2534 both sexes		
Sweden <sup>5)</sup> (Population 9.3 million)	n= 1129	n= 582	n= 547	n= 6032	n= 3675	n= 2358	n= 3796	n= 1849	n= 1847

<sup>1)</sup> Cancer Registry of Denmark (2009) <sup>2)</sup> Cancer Registry of Finland (2009)

<sup>3)</sup> Cancer Registry of Iceland (2009) <sup>4)</sup> Cancer Registry of Norway (2008)

<sup>5)</sup> Cancer Registry of Sweden (2009).

Traditional, Western medicine that follows oncology guidelines is used in treating HNC in Denmark, Finland, Iceland, Norway, and Sweden (cf. Lind et al., 2001; WHO, 2002). Detailed information on individual treatment plans was not obtained from the 35 participants interviewed for this thesis. Treatment is based on clinical factors, i.e. histological diagnosis, primary site, tumour size and spread, likelihood for total surgical resection, and potential to save speech and swallowing functions (Westin & Stalfors, 2008). Additional factors are patients' wishes, cooperation, physical function, social status, education, experience, and physician qualifications (ibid.). However, since the planning of a patient's care always involves a multidisciplinary team of health professionals, it could be difficult for the patient to sort out all these different care activities (Gil & Fliss, 2009).

Radiotherapy is standardised with 60 to 68 Grey given once or twice a day, 5 days a week, for 35 to 50 days (Rose-Ped et al., 2002). However, twice-a-day radiotherapy could limit a patient's options for ambulatory treatment and require a stay of weeks or months in a patient hotel or hospital ward. Nevertheless, continuous advancements in radiotherapy are allowing clinicians to target only the diseased tissues, i.e. intensity modulated radiotherapy (Caglar & Allen, 2007), resulting in fewer side effects compared to previous therapy (Grégoire et al., 2007). Likewise, chemotherapy has also advanced, i.e. before 1992 chemotherapy was used only to some extent as introductory treatment before surgery and/or radiotherapy (Gibson & Forastiere, 2006). Today, chemotherapy can be used as both curative and palliative treatment, or as an integral part of radiotherapy, with drugs given 5 days on three or more occasions (Choong & Vokes, 2008). Several chemotherapeutic agents and targeted therapies, e.g. antibody treatment with different toxicity profiles, are also available (Gold et al., 2009).

These treatments offer cure and/or palliation for patients, but also have side effects such as acute breathing or bleeding problems. In addition to long-term changes with swallowing and/or communication, this could cause psychosocial and existential problems for patients (Anderson & Franke, 2002; Larsson et al., 2003; Happ et al., 2004). In recent decades, services for patients' emotional and practical needs related to support, care, and knowledge have been available at ear, nose, and throat clinics (Larsson et al., 2007; Wiederholt et al., 2007; Wells et al., 2008). But these clinics are not easily accessible to everyone with HNC. Access could be complicated for some patients since they often need acute support when experiencing harsh side effects of treatment. Some authors have shown that access to health care can be difficult (Tandon et al., 2005). Frequently, patients then try to find additional treatment known to be health promoting in people with cancer (Molassiotis et al., 2006; Hök, 2009). This treatment is often referred to as complementary and alternative medicine.

However, the use of complementary and alternative medicine and traditional medicine is context-dependent (WHO, 2002). The term complementary and alternative medicine refers to a set of health care practices that are not part of a country's own traditions, or not integrated into its dominant health care system (WHO, 2002). Hence, a particular practice such as acupuncture might be referred to as complementary and alternative medicine or treatment in Western (developed) countries, while it is classified as traditional medicine in China (WHO, 2002; Hök, 2009). Traditional medicine includes diverse health practices, approaches, knowledge, and beliefs to treat, diagnose, or prevent illness (WHO, 2002). Additionally, it can incorporate plant-, animal-, and/or mineral-based medicines, spiritual therapies, manual techniques, and exercises applied singularly or in combination to maintain well-being (ibid.).

Complementary and alternative therapies such as Yoga (Kvillemo & Bränström, 2010) and human touch (Loveland Cook et al., 2004) are shown to be effective and valuable in patients with various forms of cancer, however no research could be found in relation to HNC. Both therapies integrate awareness of breathing, improved muscle relaxation, exercise, and social support, and their documented positive effects on fatigue, sleep, mood, and sense of well-being (Engebretson & Wardell, 2007; DiStasio, 2008). Since the patients have specific problems, e.g. living with deformity, perhaps complementary and alternative medicine could be used as self care to help these patients be capable of daring to present and touch their deformed face after surgery (Dropkin, 2001). Siegel (1990) stresses that an individual's attitude towards self and the power of positive thinking could be the most important factor in healing a cancer and promoting health, and this has always been an integral part of Eastern healthcare culture (Leddy, 2003).

## Everyday life with head and neck cancer

It is known that the experience of living with an illness is based on the context of the individual's reality, i.e. at home, at work, or in health care, and is related to subjective discomfort and the practical implications of life (Carnevali & Reiner, 1990). The personal uneasiness of having HNC often begins with insidious symptoms that could be similar to experiences from minor ailments, e.g. blocked nose, sore throat, hoarseness, earache, mouth ulcers, and swollen lymph glands (Feber, 2000). However the patient's symptoms progress to become a struggle of daily problems with breathing, bleeding, nose or mouth odour, eating, swallowing, fatigue, speaking, and pain in addition to changes in appearance (Langius et al., 1993, Larsson et al., 2003, Happ et al., 2004, Ledebøer et al., 2005, Caglar et al., 2008). For example, Larsson et al. (2003) described patients' eating and swallowing problems as a very specific contextual

phenomenon, and highlighted the need to focus on the patients' needs on the whole rather than treating their problems one by one (ibid.). Patients' nutritional problems often lead to extreme weight loss (Lees, 1997) in addition to fatigue (Jereczek-Fossa et al., 2007). Fatigue is a subjective, unpleasant symptom, especially during and after radiotherapy and can range from tiredness to exhaustion (ibid.). Together with pain in the shoulder and arm, due to neck dissection, it interferes with the patient's ability to perform domestic tasks (Stuiver et al., 2008). Furthermore, patients' complex communication problems, with limited speech or no voice at all, complicates life and their contact with health professionals (Happ et al., 2004). In addition, patients must often learn to live with visible disfigurement (Millsopp et al., 2006). Semple et al. (2008) suggest that patients with disfigurement could be more vulnerable since appearance affects a person's identity, self-image, ability to converse, and success in interpersonal relationships. These physical problems could lead to psychosocial consequences, e.g. changed mood, social anxiety, and behavioural avoidance that could minimize patients' sense of health and well-being in life (Anderson & Franke, 2002). Living with HNC is challenging because of its acute and long-term health consequences for those affected, and since health is such an important resource in everyday life it is important to focus on how patients can experience better health (World Health Organization (WHO), 1986).

HNC cancer corresponds to the chronic illness definition; an illness that is prolonged, does not resolve spontaneously, and is rarely cured completely (National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP, 2010]). Despite the long-term problems, patients with HNC seemed to adjust to their new situation; to live with the disease and maintain their well-being (Bjordal et al., 2001). These thoughts of maintaining well-being can be understood through the Shifting Perspectives Model of Chronic Illness (Thorne & Paterson, 1998; Paterson, 2001). This model suggests that people with chronic illness have elements of both illness and wellness that affect their life and outlook on living. This determines how people respond to the disease, themselves, caregivers, and situations, and it represents their beliefs, perceptions, expectations, attitudes, and experiences of what it means to live with a chronic illness within a specific context (Paterson, 2003). They either put the illness itself in the foreground, or they live their life in essence as a well person. The wellness-in-the-foreground perspective focuses on one's self as a person and not as a diseased body. It allows patients to distance themselves from the disease and to find meaning and hope when focusing on emotional, social, and spiritual wellness (Paterson, 2001). It permits people to rate their overall health as good even when their physical function is significantly impaired, and could provide opportunities for personal growth and change. However, keeping wellness in the foreground could also prevent individuals from getting the

service or attention they need. Consequently, patients are forced to focus on their limitations and weaknesses to receive this help, and this could threaten their integrity and sense of self (ibid.). The illness-in-the-foreground perspective focuses on the sickness, the suffering, and the loss, and patients are absorbed and overwhelmed by the illness. Health professionals are skilled in helping these individuals learn about and manage their illness or disability, and emphasise things that a person cannot do, rather than the possibilities for what they might do. The model illustrates that the perspective is not static and suggests that understanding the individual's perspective at any given time enables health professionals to provide appropriate care and support for people with either perspective (Paterson, 2003).

## Health

Health is formed, lived, and promoted by people in the settings of their everyday life; where they learn, work, play, and love (WHO, 1986). The word *health* has its roots in the word *heal*, which originally meant *whole* (Soanes & Stevenson, 2004), and implies considering a person in his/her entirety as a social being. Hippocrates (about 400 BC) described health as a condition in which the functions of the body and soul are in harmony with the outside world. Health is in a constant state of motion and change. It is valued through each individual's personal experience and can be known only through personal description (Hover-Kramer, 2002). Antonovsky (1996) defines health as a continuum between the extremes of health and disease, implying that health is present for the entire lifetime. When individuals move towards the healthier or positive end of the continuum it is called salutogenic as opposed to pathogenic. This focuses on patients' personal strengths and other health resources, i.e. salutogenic factors, and supposedly contributes directly to health and predicts favourable health outcomes (Antonovsky, 1996). This perspective of viewing health, referred to as holistic health, is represented by Nordenfelt (1995, 2007) who describes health as being related to the extent to which individuals can realise their vital goals under standard or reasonable circumstances. Furthermore, he stresses that all individuals have the right to determine and to decide what health signifies to them specifically, i.e. health relates to the affected and their situation and goal in life (Nordenfelt, 1995). However, some patients have cognitive disorders, or no strength, and then next of kin or health professionals need to act as spokespersons, look after the patient's needs, and find out what could improve their health (cf. Naue, 2008). However it is known that patients living with HNC may experience ill health from the acute and long-term side effects of tumour growth and treatment, and this could impact on their entire life situation (Bjordal et al., 2001). But every human being has his/her motives for health and the experience of health, and this relates to the person's attentiveness to their own potential, i.e. their own health resources (cf. Rundqvist, 2004). If the person

feels well and can function in his/her social context, then that is their experience of health and feeling of well-being irrespective of illness or health condition (Nordenfelt, 1995).

## Health promotion

The concept of health promotion is a theoretical concept and has been interpreted in many ways (cf. Medin & Alexandersson, 2000). It is viewed and used differently, reflecting different perspectives, traditions, and approaches towards working with health promotion in practice. Expressions such as equality, partnership, collaboration, participation, self-determination, mutual responsibility, and empowerment are used in the Ottawa Charter when describing health promotion (WHO, 1986). Health promotion is a positive concept emphasising personal, social, political, and institutional resources, as well as physical capacities. As such, it is not a responsibility for the health services alone, since subjective feelings of health and well-being are a necessity and require participation from the individual self (ibid.).

Leddy (2003) highlight to look at the patients as active individuals with strength to decide for themselves what they think promotes their health. Rundqvist (2004) asserts that the human being's power lies in his/her inner strength, i.e. the ability to be free to act, which also implies ability to refrain from acting. Some describe health promotion as being consistent with the disease perspective, which is based on risk factors that cause disease, i.e. a pathogenic perspective (cf. Tones & Tilford, 1994). In this context, the patients in focus are recipients of information and education from health professionals who inform about risk factors, e.g. smoking that could cause biological changes resulting in disease, and encourage health activities that could prevent ill-health or promote health. Though, health promotion in relations to patients with HNC could mean that an individual's viewpoint defines what counts as healthful. This is a transformation from expert-driven care to patient-centred care (Young & Hayes, 2002). Although this perspective involves education and information, it emanates from the patient's own questions and overall life situation (ibid.). For instance, giving up smoking or alcohol is a reliable way to prevent and lessen the recurrence of some HNC (Dikshit et al., 2005). Further, smoking and alcohol cessation involve better physical prerequisites, stronger personal finances, and perhaps strengthen the patients' self-esteem. This could promote the patient's progress in achieving vital goals; hence entailing health promotion. Yet, giving up these habits will not directly lead to achieving vital goals in life; nor will it spontaneously reinforce a patient's ability to act (cf. Aarstad et al., 2007). Further, Allison's (2002) research shows that using (as opposed to abusing) wine during recovery can lead to better physical and role functioning, less fatigue, and a decreased sense of illness.

It is also known that intake of citrus fruits could be protective and reduce the risk of developing of a secondary primary tumour in the lung (Dikshit et al., 2005), but often patients' anatomical problems make it impossible to eat the recommended food (Larsson et al., 2003). Pender's (1996) opinion about health professionals' health promotion activities is in line with this thesis; that health promotion is not restricted to information and education about prevention. Rather, health promotion aims to, and includes, advocating health wishes and intensifies patients' positive potentials for health. Berg et al. (2006) assert that patients (hospitalised elderly) perceive health as being able to be the person they were, to do what they want, and feel well and have strength. They view health promotion as being enabled – through the person they were, through information and knowledge, and through hope and motivation (ibid.). Hartrick (2002) points at the significance of relationships in health promoting practice and asserts that health professionals ought to work in partnership with their patients as relational beings, i.e. health promotion is a matter of power distribution and joint responsibility. Furthermore, Richardson (2002) reports that effective communication, understanding, and insight were experienced as enhancing health and well-being for patients in HNC care. Wells' (1998) research reveals that some patients with HNC have resilience and profound reluctance to ask for help, despite extensive physical and emotional trauma. Perhaps this is not necessarily attributable to characteristics of the patient. Research shows health professionals' behaviours, e.g. rejection, annoyance, and being stressed could discourage patients from expressing their needs (cf. Halldórsdóttir & Hamrin, 1997). To experience feelings of a positive human encounter when receiving care, patients need respect and balance in every care contact with health professionals (NIPH, 2005). Consequently, perhaps patient-centred care (Institute of Medicine (IOM), 2000) and accessible information could strengthen hope and motivation and help these patients build the strength to decide to act and ask for help if and when they need it.

This corresponds to the Ottawa Charter, which underlines the individual's own activities in the health promotion definition – a process of enabling people to increase control over and to improve their health, i.e. empowerment (WHO, 1986). Empowerment is a multi-dimensional social process. At the core is the idea that we could accept that power can change and expand and make empowerment possible (Page & Czuba, 1999). Empowerment is part of health promotion and as such is said to be essential, implying a mobilisation of individuals (and groups) by corroboration of their basic life skills and enhancing their decisions and actions affecting their health (Nutbeam, 1998).

Empowerment is strongly connected to the idea of holistic health (cf. Dossey et al., 2000), in particular when defined as the ability to act to realise vital goals

(Nordenfelt, 1995). Empowerment may also be understood to promote health if it implies the growing capability of patients to succeed in their self-formulated goals, with an outcome of better health (cf. Rappaport, 1985). This concept encompasses the idea that people can form relationships with others, and that the empowerment process could be similar to a journey that develops as we work through it (Leddy, 2003). Mok et al. (2004) revealed that empowerment leads to increased self-determination, self-worth, creation of autonomous decision-making, and ultimately a mastery over and acceptance of the illness and the meaning in everyday life.

## Other related concepts

The concept of sense of coherence includes components such as comprehensibility, manageability, and meaningfulness (Antonovsky, 1987). Comprehensibility is the extent to which a person perceives the world as being predictable, ordered, and explicable. Manageability is the extent to which one believes that he or she has the personal and social resources to handle a demand. Meaningfulness is the belief that demands are challenges worthy of investment and commitment (ibid). The stronger the sense of coherence in life, the more probable the individual will be able to cope effectively with demanding life situations, which in turn leads to better health (Langius et al., 1992).

Coping is defined as constantly changing cognitive and behavioural efforts (i.e. coping strategies) to manage specific external and/or internal demands; actions intended to deal with and overcome difficulties (Lazarus & Folkman, 1984). Coping strategies are often divided into two categories; problem-focused and emotion-focused. Problem-focused coping strategies deal with concrete actions; seeking information, discussing problems, setting goals, or letting someone else solve the problems. Emotion-focused strategies are used to manage emotional suffering derived from stress-related situations and may involve the use of, e.g. crying, worrying, humour, or drugs. Coping could also focus on personality in the coping process, e.g. the sense of coherence that could lead to successful management of stressors; self-esteem, self-efficacy, self-determination, and hardiness (Langius & Lind, 1995; Aarstad et al., 2008).

Self-esteem means confidence in one's worth or abilities (Soanes & Stevenson, 2004) and is closely related and intertwined with integrity that relates both to autonomy and a relationship to oneself and to others (ibid.). Self-efficacy is characterised by the individual's judgement, e.g. some think that being healthy is of significance, and the belief in oneself leads to that outcome (Bandura, 1982). Self-determination is enabled through the possibility to participate and make one's own decisions, weigh advantages versus disadvantages, negotiate, and make choices (Thomas & Velthouse, 1990). A greater sense of self-

determination may reinforce greater meaning in life since meaning serves as the engine of empowerment (ibid.). The concept of hardiness includes the components of commitment, control, and challenge, and an individual with high ratings has a resilient personality, which may relate to subjective health (Kobasa, 1979; Aarstad et al., 2003).

Brülde and Tengland (2003) state that health, health promotion, and quality of life are complementary and overlapping and refer to subjective evaluation, which induces both positive and negative dimensions embedded in a cultural, social, and environmental context. Quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (cf. WHO, 2010). Health-related quality of life has been defined as the effect of individual health on physical, mental, and social functional ability. This definition includes subjective well-being, satisfaction, and self-worth (Bowling, 1997). Hence, quality of life relates to empowerment since it embraces self-esteem, a positive view of the future, a sense of power, and an actual ability to affect one's situation through action both in private life and in society (cf. Birkhaug et al., 2002).

## Rationale of the study

The findings of the studies in this thesis aim to enhance knowledge and increase our understanding of HNC patients' experiences of what they felt promoted health and well-being. The intent is to describe the 35 participants' experiences from a health promotion and salutogenic perspective. There is value in focusing on patients' personal strengths and other health resources, though possessing a sense of better health and well-being could be of significance for patients as they endure their vulnerable situation.

An increasing number of people are contracting HNC and patients face both acute and long-term chronic complications from the illness and side-effects from treatment. These factors reflect the illness burden for patients and their next of kin, and need for continuing and long-lasting access and support from healthcare and society. These people constitute a vulnerable group since HNC often causes visible disfigurement combined with speech and eating disorders that could also lead to psychosocial problems. Such characteristics underline that this fairly large group in society could be a concern of public health services.

In view of this, it was important to reach a deeper understanding of how patients could find a balance between ability, demands, and actions for realising their vital goals, under realistic conditions, during this long-term illness. This goes far beyond a superficial knowledge of the situation – it means trying to understand

and enter into the affected individual's experiences and sphere of thinking, trying to gain insight and share feelings of another individual and understand the meaning that he or she attaches to a phenomenon.

## Aims

This thesis aims to reach a deeper understanding of living with head and neck cancer and to identify the experiences that patients felt promoted their health and well-being.

### Specific aims:

- to describe cancer patients' experience of nurse behaviour in terms of critical incidents after nurses had given them health promoting care (paper **I**).
- to describe the characteristics of health promoting contacts with health professionals as encountered by individuals with head and neck cancer (paper **II**).
- to shed light on health promotion from the perspective of individuals living with head and neck cancer (paper **III**).
- to illuminate what it means to live with head and neck cancer (paper **IV**).

## Methods

### Design

A qualitative research design was chosen since this type of design generates an awareness of human experiences, as expressed by the individuals themselves in their natural context (Lincoln & Guba, 1985). The design is flexible, and the researcher is the tool for data collection and analysis while engaging in ongoing reflection and decision-making throughout the studies' progression (Polit & Beck, 2008). Consequently, this can lead to further research based on realities and viewpoints that were not known or understood at the outset of the research (Lincoln & Guba, 1985). The studies in this thesis employ different qualitative methods. The first study was conducted in Denmark, Finland, Island, Norway and Sweden, with one individual from each of the four participating Nordic countries and 17 from Sweden (paper **I**). Since costs, logistics, and time would have been prohibitive in conducting a qualitative follow-up study in five countries, the remaining studies (papers **II**, **III**, **IV**) focused on the Swedish

HNC care context. Also, it was not my intention to conduct comparative research between the countries. Table 2 presents an overview of the four papers.

**Table 2 Overview of papers I to IV**

Paper	Participants (n= 35) male/female and countries	Method of data collection	Method of data analysis
<b>I</b>	n=21 (13 men and 8 women) n=17 from Sweden and one from each of the four participating Nordic countries	Audio taped semi-structured qualitative interviews	Critical incident technique
<b>II and III</b>	n=8 (4 men and 4 women) Sweden	Audio taped semi-structured qualitative interviews	Qualitative content analysis (thematic in <b>II</b> and latent in <b>III</b> )
<b>IV</b>	n= 6 (4 men and 2 women) Sweden	Audio taped semi-structured qualitative interviews	Interpretative descriptive analysis

## Study context

The first study was conducted from 1997 through 1998 in the Nordic countries (paper **I**), the second study during 2005 in Sweden (papers **II**, **III**), and the last study was conducted from 2005 through 2007 in Sweden (paper **IV**). All participants had received or were receiving treatment for HNC, i.e. surgery, radiotherapy, or chemotherapy at their regional oncology centre or local ear, nose, and throat clinic. During these treatment periods the patients had contact with numerous health professionals, i.e. different surgical, radiation, and medical oncology experts, dentists, pathologists, physiotherapists, speech therapists, social workers, dental hygienists, dieticians, and nurses. Healthcare policies concerning the treatment of HNC in the Nordic countries have changed during the past decade, from inpatient care in general to short hospital visits and outpatient care. In addition, policymakers have stipulated sharper guiding principles towards more health promoting care (NPH, 2009).

## Participants

All patients (n= 35) interviewed for this thesis were purposively selected in consultation with medical and nursing staff involved in their care.

The selection criteria were:

- Men and women above 18 years of age
- Willingness and interest to verbalise and communicate their own experiences
- Diagnosed and treated for different forms and stages of HNC
- Curative or palliative treatment of HNC

Nine of the patients (6 men and 3 women) originated from seven countries outside of Sweden (Southern Europe, Middle East, and other Nordic countries). Of the 21 men (aged 38-83 years; median 62.6 years) 15 were married or cohabited, two lived apart, and the rest were divorced, widowed, or single. Of the 14 women (aged 59-81 years; median 65.4 years) nine were married or cohabited, one lived apart, and the rest were divorced, widowed, or single. All but two men and two women had children, and several had grandchildren. One participant was unemployed, and 14 were employed, one was a student, five had disability pension, three had early retirement pension, and eleven were retired.

Of the patients who chose not to participate 12 were men (aged 35-65 years; median 48.6 years) and seven were women (aged 32-80 years; median 55.7 years). Six men and four women of those initially asked chose not to participate in the first study (paper **I**), and six men and three women chose not to participate in the second study (papers **II**, **III**). All agreed to participate in the last study (paper **IV**).

Table 3 presents an overview of the diagnoses of patients that participated in studies conducted for this thesis. The table was designed to include the specific diagnoses while ensuring the confidentiality and integrity of all participants when grouped together.

The most common diagnoses were tonsil cancer (6 men, 1 woman) and larynx cancer (4 men, 2 women). The most frequent accompanying diagnosis was cancer in the floor of the mouth (2 men, 2 women). Five participants had additional forms of solitary cancer in other parts of the body.

Table 3 Overview of the 35 participants' diagnosis

Diagnosis	No. of participants	Male/female
Cheek cancer	3	3/0
Epipharynx cancer	1	0/1
Gingival cancer	2	0/2
Laryngeal cancer	6	4/2
Lip cancer	1	1/0
Mandible cancer	1	1/0
Maxilla cancer	2	1/1
Mouth bottom cancer	2	1/1 (2/2) <sup>1)</sup>
Nasal cancer	1	1/0
Oropharyngeal cancer	1	0/1
Unspecified head and neck cancer	2	1/1
Oesophagus cancer	0	0/0 (0/1) <sup>1)</sup>
Salivary gland cancer	1	0/1
Tongue cancer	4	2/2
Tonsil cancer	7	6/1
Thyroidal cancer	1	0/1
<i>Other</i> solitary cancer in the body	5	2/3 <sup>2)</sup>

<sup>1)</sup> The participants' side diagnoses are indicated in brackets

<sup>2)</sup> Prostate, stomach, breast, lymphoma, melanoma, cancer

In nearly half of the participants ([n= 15] 7 men and 8 women) the cancer had not spread, but nearly all patients had large tumours. Eighteen participants had lymphatic gland metastases and eleven had recurrence near the first tumour. Seven had both metastases and recurrence. This displayed the severity of the HNC sickness and could have impacted on both the unique patient's everyday life and on the next of kin who shared his/her experiences. Some of the patients' problems, symptoms, and changes could be particularly unpleasant, for instance:

- 33 participants experienced eating and swallowing difficulties
- 31 participants had visible tumours or skin defects in the face or neck after surgery or radiation
- 20 participants had hoarseness
- 18 participants had increased phlegm with coughing or spitting, or no saliva and dry mouth
- 16 participants had articulation problems
- 5 participants who had undergone laryngectomy had pseudo voice
- 4 participants had nasal voice

## Interviews

All studies were based on individual, open-ended, semi-structured, qualitative interviews (Kvale, 1996). A semi-structured guide with written topics for all studies was developed in advance, reflecting the author's interest in everyday life, especially in what promotes better health and well-being for patients with HNC. In the first study, a semi-structured interview guide was constructed by following Flanagan's (1954) advice, i.e. questions were derived from the aim of the study (paper **I**). After one test interview, both the technique and the questions proved to be satisfactory and were included in the study. In the second study, a semi-structured interview guide was constructed and used, and three test interviews were conducted. Since these were unsatisfactory, the guide was divided into two areas, one to cover the topic for paper **II** and one for paper **III**. After the revisions, all participants were re-interviewed using the two-part guide. The first three test interviews were included in the respective participant's interview. A semi-structured guide was constructed for the last study. One test interview was conducted and showed the guide to be useful. Hence, the interview was included in the study (paper **IV**). In this last study, the interviews were repeated and extended over 1-year illness experiences, dissimilar in points in time for each participant. Table 4 present an overview of the fifty-three interviews that were conducted in total.

Table 4 Overview of the interviews (n=53)

Paper	Interviews	Year of the interviews and length of the collection period	Time after initial diagnosis or recurrence	Length of interviews (minutes)
<b>I</b>	n=21	1997-1998 18 months	120 days -14 years	30-90
<b>II and III</b>	n=8 +3 <sup>1)</sup>	2005 7 months	45-270 days	60-120
<b>IV</b>	n=21	2005-2007 19 months	7-30 days <sup>2)</sup>	50-75

<sup>1)</sup> Three test interviews were performed and included. <sup>2)</sup> Interviews with the two participants that had recurrence were performed 5 and 9 months after the initial diagnosis.

## Interview process

All patients (n=35) gave their written consent before the interviews and chose the time and place for their interview. Some patients were interviewed once (papers **I**, **II**, **III**), while others were interviewed up to four times (paper **IV**). The patients were interviewed at their homes (n=30), at hospitals (n= 21), or at their place of work (n=2). Since it could be problematic to interview patients with impaired speech, sufficient time was allowed to reach an understanding. The interviewer focused on topics, however the participants were allowed to talk freely about topics and narrate in their own words. Problems could arise because Swedish was not every patient's native language. Hence, parts of some interviews were conducted in English. Neither the participants nor the interviewer (the author of this thesis) had English as their native language, but all were familiar with the language. Body language was also used frequently, e.g. facial expressions, lip movement, or pointing to the body to describe surgery, pain, disgust, or cheerfulness. Some participants had next of kin nearby during the interview, but comments from next of kin were included only if the participant asked them to fill in words and gave a nod of approval. Several of the participants glanced through private diaries or at photographs or brochures during the interviews to trigger memories of their illness experiences. Additionally, some participants clarified their answers in writing. All discussions during the interviews were tape recorded. Nevertheless, most participants spoke freely with the tape recorder present and seemed to disregard it after a short period. The interviews lasted 30 to 120 minutes, but contact time with the patients was substantially longer. The author of this thesis transcribed the tapes verbatim in the days following the recorded interviews. At that time she could recall her experiences of the interview situation and if necessary add small notes to the transcripts of what happened, e.g. when participants experienced episodes of coughing or crying. This helped capture the illness impact on the participant's entire body. The transcriptions yielded 1083 pages (1.5 spacing).

## Text analyses

Owing to the richness of the text and the ability to interpret the data on different levels, different qualitative analyses were used to interpret the collected information. Qualitative content analysis is an interpretation process that focuses on similarities in and differences between different parts of text that lead into categories and/or themes (cf. Graneheim & Lundman, 2004). A category contains several codes with similar content that answers the *what* question and relates to the content on a descriptive level. A theme answers the *how* question, i.e. the 'red thread' throughout the condensed meaning units, codes, or sub-categories (Polit & Beck, 2008 p. 517). A meaning unit is a constellation of

words or statements that relate to the same meaning, and codes are a process of identifying recurring words, themes, or concepts within these meaning units. Burnard (1995) claims that there are different levels or dimensions of interpretations ranging from the concrete surface level of words used down to the deeper level of meaning. The researcher's pre-understanding was treated as a part of the interpretation process as well as a tool to guide it. Consequently, the text analysis was open to several possible interpretations. The first study was analysed with the critical incident technique (Flanagan, 1954) (paper I), the second study with a qualitative content analysis, i.e. the thematic in paper II (Baxter, 1991) and the latent in paper III (Berg, 2004). The last study was analysed with an interpretative descriptive analysis (Thorne et al., 1997; Thorne et al., 2004) (paper IV).

### Critical incident technique

In 1954, Flanagan described the critical incident technique that has been used in healthcare research, e.g. by Benner (1984), Rooke (1990), and Svensson and Fridlund (2008). This method obtains data from participants by in-depth exploration of critical incidents and human behaviours related to the topic under study (Flanagan, 1954). The technique differs from other self-reported approaches as it focused on something specific that the participants can likely give evidence on as an expert (Polit & Beck, 2008). It includes a detailed description of the situation that led to the incident, action, or behaviour, and the result. This study aimed to describe cancer patients' experiences of nurses' behaviour in terms of critical incidents after nurses had given them health-promoting care. A critical incident was defined as an event of great importance to the patient, which had either a positive or negative impact on the patients' experience of feeling better health and well-being. All incidents were classified into groups and reformulated into different types of actions, i.e. sub-categories. These sub-categories were allocated into the nurses' behaviour, i.e. categories. The categories were then placed into one of the main areas (paper I).

### Qualitative content analysis

The following content analysis of narrative data aims to identify prominent themes and patterns among the themes (Polit & Beck, 2008). It involves breaking down text into smaller units, and coding and naming these units according to the content they represent. Thereafter, the coded material is grouped by focusing on similarities and differences. The thematic and latent qualitative content offers alternatives for analysis, and Sandelowski (2000) asserts that researchers can use wording to develop qualitative descriptions when analysing the different qualitative content of text. In the second study, the transcribed text was analysed using both thematic (Baxter, 1991) and latent

qualitative content analysis (Berg, 2004). Since the aim was to describe patients' experiences of those features of a contact with health professionals that could increase their feelings of better health and well-being, the researcher needs to reflect on the context (paper **II**). Hence, it seemed appropriate to use thematic content analysis since Baxter (1991) claimed that this analysis always includes a total picture of the circumstances under analysis. The questions to patients were asked in positive sentences, but throughout the process of identifying meaning units the analysis revealed both positive and negative experiences and even the desire for health promoting contacts. For that reason the text was divided into two parts and named *health promoting contacts* and *not health promoting contacts*. The latter includes participants' wishes for health promoting contacts, since these were not experienced contacts, but they might broaden the findings on the meaning of the concept. Also, as a basis to provide opportunities for amplifying knowledge about health promoting contacts, it seemed important to know what the participants thought promoted health and well-being. Then the meaning units were grouped according to which period in the participants' illness trajectory they belonged, and were then condensed and labelled with a code. All coded data were grouped together based on their similarities and differences, and ultimately three themes were named (paper **II**).

Latent qualitative content analysis was used since the aim was to shed light on health promotion from the perspective of individuals living with HNC, i.e. the experiences of what the patients' felt promoted their health and well-being (paper **III**). This seemed to be appropriate since according to Berg (2004) it involves interpretative reading of the representation of what is essential in the text to reveal the deep structural meaning conveyed by the message. The first reading revealed that health could be promoted in three ways; by means of oneself, by family and others, and by various activities. The meaning units were marked, condensed, and labelled with a code, and the codes were sorted into sub-themes. A search was conducted for a pattern in the sub-themes, and the themes were named. Every theme was further analysed, and one main theme could be formulated (paper **III**).

### Interpretative descriptive analysis

Before the final study began (paper **IV**), the findings and methods used in the other studies were discussed in attempting to form a critical review and basis for a preliminary analytic framework (Thorne et al., 2004). The pre-analytic understanding was that the findings had in some way captured the experiences of 35 HNC patients as regards contact and care involving health professionals, and the patients had reported when these contacts had promoted health and well-being. Some patients, however, reported negative experiences, e.g. being

exposed and vulnerable in contacts with health professionals. The findings also mirrored the patients' process of empowerment by being enabled to act and take control over everyday life with help from internal and external resources (papers **I, II, IV**).

Although patients were obviously troubled by tumour location and the side effects of treatment, which placed a heavy burden on everyday life, none of the studies revealed this profoundly. This pre-analytic understanding revealed a need for deeper understanding of what it meant to live with HNC. It was decided to repeat the interviews with a small sample of patients and follow, for one year, the unique experiences of individuals living with the illness.

Already during the interviews the narrated stories revealed the individuality of what it meant to live with HNC, and therefore each patient's text was analysed and coded separately. Likewise, Thorne et al. (2004) conveyed the importance of respecting the contextual nature of the text and focusing on the intellectual processes that are cornerstones in qualitative data analysis. The interview text was rich and deep in structure, and the author moved in and out of the text, critically examining the initial codes by asking questions such as: What was said here? What, where and when did it happen? What does/ could it mean for this person? By changing between the codes and the exclusive patient's complete text, the progression of understanding evolved from the surface to a deeper level of interpretation. From this investigation to uncover patterns in the text grew an interpretation of sub-themes from each interview, and these were further analysed when looking for changes over time. After that, one theme was interpreted for the complete transcript of each unique patient. In the final stage, a main theme was interpreted, i.e. an association that could mirror living with HNC for all the patients (paper **IV**).

### The author's pre-understanding

I am a registered nurse with over 25 years of experience in working in an ear, nose, and throat clinic that treats patients in different stages of HNC. Additionally, for the past decade I have been a lecturer, teaching e.g. health science, nursing and oncology proficiency. My pre-understanding was a requirement for performing the interview studies, given my practical knowledge of the care context and the communication problems that these patients can encounter. I was also aware that individuals in this group of patients are vulnerable when meeting strangers, due to their changed appearance or other issues, e.g. coughing and spitting necessitated by increased phlegm. I have grown proficient in shaping a dialogue and participating in and providing equality in the interview situation. Also, I dare to bring up and discuss how

patients could feel when being placed in a dependent care situation. I know the importance of being an attentive listener, respecting the patients' life situation, and paying attention to their will to communicate. I recognise the need to probe and to prolong the waiting time for answers, not necessarily verbal but also responses expressed in body language or in writing.

My pre-understanding about living with HNC and my concept of health promotion has changed during the work on this thesis. As a consequence, the concept of health promotion is not equivalent in my studies. I realise that as a health professional you can perceive, but not experience, the inner feelings and needs associated with having an illness. This awareness can grow and be used as part of caring or the interpretative research process. Since my pre-understanding could interfere with the findings, this should be taken into consideration especially regarding the concept of health promotion.

## Ethical considerations

The Lund University Ethics Committee (LU, 348/1997, LU 772/2004) approved the studies in Sweden. In the other Nordic countries, chief physicians at the regional ear, nose, and throat hospitals where the patients had been treated were informed about the studies and agreed to its implementation. All studies complied with ethical principles, i.e. the principles of respect for autonomy, non-maleficence, and beneficence (Beauchamp & Childress, 2001, Northern Nurses Federation [NNF], 2003, World Medical Association [WMA], 2004). The data collected were coded and kept in strictest confidence, and the participants were guaranteed confidentiality in the presentation of study findings. The first study revealed no unique details, e.g. diagnosis together with country, age, and gender (paper **I**). Participants in the next two studies were treated in a specific area of southern Sweden, and it was important to act with strict confidentiality (papers **II**, **III**, **IV**). The author was careful not to reveal the specific diagnosis, age, gender, the exact day when the interviews were performed, or other such details. Participants who originated from other countries, but were living in Sweden, were not referenced in terms of mother country or language. Confidentiality was also explained to next of kin if they were present during the interviews.

### Principle of respect for autonomy

In all the studies, patients were presented with a written form asking if they would be willing to participate and be interviewed. In the first study, the form

was written in their native language, but the open interview questions were posed in Swedish, English, and occasionally in the participants' native Nordic language (paper **I**). The author of this thesis provided verbal information about the study and obtained the patients' written, informed consent before they enrolled. The participants also gave oral informed consent before the repeat interviews in the final longitudinal study (paper **IV**).

All patients were informed that their participation was voluntary, and that they could withdraw at any time during the research process without explaining the reason, and with no consequences to usual care. The patients' physical and psychological conditions received special attention, and added value was shown to severely ill individuals. Since many of the participants had difficulty speaking, an attachment to the written form encouraged them to use the interviewer's telephone number, address, or e-mail if they wanted to raise questions or leave the study, but no participant made such a request. On occasion participants asked to postpone the interview, and death precluded some interviews (paper **IV**).

## Principles of beneficence and non-maleficence

When conducting qualitative research with patients who are in vulnerable life situations the principles to do no harm and to do good are highly important and were applied in this research, e.g. when taking the individual's very specific speech impairment into consideration (cf. Philpin et al., 2005). Hence, the same interviewer with extensive working experience as a nurse in this care context conducted all the interviews. Potentially, problems concerning physical ability, language, or culture could have arisen, but none did. The interviewer made a concerted effort to respect and intuitively perceive the needs of the individual participants. The interviewer waited for responses and encouraged the participant to talk during the interviews, showing flexibility when participants felt tired or found it necessary to use body language or mime words. These factors could have contributed towards the successful execution of the interviews.

## Findings

The deep understanding of living with head and neck cancer (HNC), and the experiences of what the patients felt promoted health and well-being, was interpreted as *having strong beliefs in a future in face of living on a rollercoaster*. This interpretation was built on the patients' experiences of the unique impact of HNC, its threat against their identity, and an existence with swiftly changeable feelings oscillating between hopelessness and hopefulness (paper **I, II, IV**). Inherent in these feelings were the patients' struggle and orientation towards the health, power, and control that offered them belief in the future (papers **III, IV**). Yet the findings also revealed the opposite – that some patients showed less energy and a sense of facing insurmountable barriers against achieving feelings of health. Hence, they felt less command over life and less belief in the future (papers **III, IV**).

All participants' experiences were of course based on their specific everyday situations. Hence, their capacities, difficulties, needs, and access to support differed substantially. Many of the participants felt vulnerable, exposed, and even disempowered in their contacts with health professionals. Especially before and after treatment they experienced feelings of being alone, abandoned, and insecure.

Nevertheless, inherent in the interpretation was their search for ways to promote health and well-being, although they experienced this as a means to find ways of thinking about a future life. The success of this work was interpreted as depend on their connection with enabling, which could involve internal motivation to act i.e. internal strength, and external resources, i.e. when others stimulate him/her to engage in processes to look forward (papers **I, II, III, IV**).

Table 5 summarises the findings. As is apparent, the author's pre-understanding of the health promotion concept is not equivalent in the studies. The first study revealed her traditional biomedical and pathogenic standpoint; dependent, of course, on the aim of the study. The nurses engage in monitoring, caring, inspecting, observing, informing, and educating patients about risk factors in the context of health promotion activities, helping patients cope with the environment to reach well-being. In the subsequent studies, the affected individuals' perspectives on living every day with HNC dominated. These findings are rooted in the affected individuals' activities and experiences of what they thought promoted their own health and well-being.

Table 5 Summary of findings

Paper	Aim	Main areas/ main themes	Categories/themes	Sub-categories/sub-themes
<b>I</b>	To describe cancer patients' experiences of nurses' behaviour in terms of critical incidents after nurses had given them health promoting care	Cognisance	The nurse supervised	The nurse checked up on the patients' nutritional status, cared for the patients' personal hygiene, observed, inspected the patient
			The nurse demonstrated knowledge of her profession	The nurse cared about nursing, technical, and medical issues, and knew her own limitations
			The nurse brought enlightenment	The nurse informed about social issues, nutrition, smoking, treatment, and side effects, and instructed about medical issues
		Solicitude	The nurse made participation possible	The nurse allowed the patient to co-operate; take responsibility for health, and make their own decisions
			The nurse showed personal consideration	The nurse was obliging; encouraging, respectful, gave physical assistance, and showed empathy
			The nurse was supportive	The nurse was thoughtful, consoled, and answered the call-bell
<b>II</b>	To describe the characteristics of health promoting		Being believed in one's illness story	
			Having a working relationship with health professionals	

	contacts with health professionals as encountered by individuals with head and neck cancer		Receiving individualised, tailored care	
III	To shed light on health promotion from the perspective of individuals living with head and neck cancer	The ability to regain control and empower oneself	Being enabled by dialogue with one's inner self	Transformed and improved self-esteem, recognising and embracing existentiality, increased self-determination
			Being enabled by means of contact with a social network	Emotional support, practical support
			Being enabled by means of contact with, and a passion for, the environment	Nature, hobbies, and activities
IV	To illuminate what it means to live with head and neck cancer	Living in captivity	Altered sense of affiliation	Trapped in an alien body, taking actions to explore new life conditions, isolation and changed relationship, spiritual confidence and faith
			Hostage of health care	Feelings of being disregarded in treatment decisions and being a guinea pig
			Locked up in a broken body, but with a free spirit	Existential disequilibrium, perceived rejection by next of kin, self-induced isolation, death as transition

Confined in a rogue body	Being afraid of choking during sleep, necessity of restrictive living, preparing for own death and next of kin's security
Forced to depend on others	Living on a rollercoaster, left at the mercy of healthcare professionals, living in a compromised state, reconciliation with the illness
Caught up in a permanent illness trajectory	Confidence in health care, threatened by legal proceedings, lack of accessibility and continuity in health care, financial problems and cancer are a family affair

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The most important findings will be presented under the following headings: **living with head and neck cancer; experiences of what promotes health and feelings of well-being; and experiences of what hinders health and feelings of well-being.**

## Living with head and neck cancer

The findings showed that for many of the patients' (n=35) experiences of living with HNC meant an existential loneliness, and was interpreted as a unique and complex feeling, not unlike that of living in captivity (paper **IV**). This imprisonment was a result of the participants' illness-related experiences of living alone in existential insecurity and encapsulation, reliant day and night on how the illness impacted their vital needs for survival, e.g. physical attributes making it difficult to breathe, eat, and swallow. Although the physical impact could reveal similarities, it always involved unique experiences that were (1) *physically*, (2) *emotionally*, (3) *socially*, and (4) *existentially* confining for the patient (paper **IV**).

(1) *Patients experienced physical confinement* when choking sensations and extreme swelling in the throat forced them to exhibit ungraceful behaviour, e.g. massive phlegm stagnation resulted in constant hawking, clearing of throat, and spitting, and they felt trapped in an alien body (papers **I, IV**). These feelings were intensified and interwoven with their changed appearance and dependence on technical and medical devices, e.g. feeding tube and/or tracheal tube (papers **I, II, III, IV**). Further, it was understood that feeling breathless made patients extremely anxious, and they were afraid of choking during sleep. This discomfort mirrors confinement in a rouge body (paper **IV**).

(2) *Experiences of emotional confinement* were revealed when hovering between despair and hope, where patients first had a sense of uncertainty, anxiety, and depression, and then experienced a swing in the opposite direction. It was as if they were living on a virtual rollercoaster. Their feelings of despair intensified when needing an alter ego to deal with the complexities of speaking, and the findings revealed living in a compromised state (paper **IV**). The experiences of hope were most noticeable in comforting meetings with next of kin, good friends (paper **III**), and sometimes with health professionals that gave them emotional support (papers **I, III**).

(3) *Experiences of social confinement* were revealed when eating difficulties and disfigurement altered the patients' interactions and encounters with others. In social encounters it was understood that the patients were met by stares or avoidance in addition to changed attitudes and reactions, even from their circle of acquaintances, and they felt an altered sense of affiliation (paper **IV**). It was not uncommon that they preferred to be alone and limited their social life to conserve energy (paper **III**), and the findings revealed this self-induced isolation (paper **IV**). Some patients felt that the social circumstances that forced them into dependency on others also made them vulnerable, and they felt as if they were trapped in a social net. The distribution of domestic work changed, affecting everyday life for both the patients and their next of kin (papers **III, IV**). Furthermore, their life could be affected by financial problems because both the patients and their next of kin experienced increases in the cost of living, e.g. medicine, treatment, special diet, travel expenses, or inability to work (paper **IV**). The patients often shouldered the responsibility for protecting their total family's economic situation and the findings revealed that they looked ahead to prepare for their own departure and their next of kin's future economic security (paper **IV**). The findings showed that the patients' working life changed (paper **I**). Further, feelings of harassment from employers when being on sick-leave, no consideration given to their new life situation, and feeling threatened by legal proceedings (paper **IV**).

(4) *Experiences of existential confinement* were revealed when unemployment seemed to affect the patients with feelings of existential disequilibrium, and they presented spiritual beliefs that their total life situation had brought forth the latent cancer in their body (paper **IV**). Patients developed an existential loneliness and feelings of living in the land of the sick (paper **IV**); an experience amplified by the patients' perceived rejection by next of kin and changed sexual relationship (paper **IV**).

## Experiences of what promotes health and feelings of well-being

The findings revealed the patients' unique willpower to fight for something that could enhance their feelings of better health (paper **III**). The patients' focus could be understood as an endeavour to improve health and to find hope, i.e. to achieve the best possible well-being to fulfil new life goals of health (papers **I, II, II, IV**). The ability to reach goals for better health was connected to factors such as the patients' (1) *internal* and (2) *external enabling* to regain control and empower oneself (paper **III**).

### (1) Ability to reach internal enabling

Factors that impacted on the patients' internal or intra-personal ability to enable and use inner strength could be observed in the dialogue with the inner self when the patient practised mental training and praying. They learned to use their inner potential and adeptness to discover and take charge of solving their own problems by their transformed and improved self-esteem (paper **III**). Internal enabling was connected to thoughts and persona of how they looked at their existence and self, i.e. their self-confidence and self-image, and this seemed to impact on their ability of self-determination (paper **III**). As a result, the findings revealed an intention not to act as a victim of circumstance, but to somehow reconcile with the illness. They actively took action to explore new life conditions and felt a need, and were relieved, to meet soul mates having similar experiences (papers **III, IV**). The patients seemed to recognise and embrace existentiality and to be totally focused on being present in the here and now as a grateful survivor (paper **III**). Further, the findings revealed patients' free spirit and spiritual confidence and faith with no fear of dying and the conviction of re-incarnation and death as a transition (paper **IV**).

### (2) Ability to reach external enabling

Factors that impacted on the patients' external or inter-personnel enabling of ability were revealed in support from **(a)** social networks **(b)** contact with environment, **(c)** and health care. Helped by these external enablers, the patients could reach their own strength and form and enhance their health.

**(a)** Being enabled by means of contact with a social network was revealed as *emotional* and *practical support* from the patients' next of kin and close friends (paper **III**). *Emotional support* 24 hours a day was particularly precious – to have one important person to talk to, someone who dared to listen and contained their fears when the patients' thoughts were in turmoil from their sickness and existence (papers **III, IV**). The patients revealed cheerful, humorous, and amusing interactions that gave them strength and motivation to live, and they revealed that having HNC was a family affair (papers **III, IV**). They also revealed the *practical support* they received, e.g. assistance with household work, personal hygiene, and phone calls.

**(b)** The patients' external enabling of ability was revealed by means of contact with and appreciation for the environment, categorised as *nature, hobbies, and activities*. *Nature* was understood to have a healing power, and when being outdoors in any weather conditions the patients enjoyed nature's colour and peacefulness. Outdoor activities seemed to increase the patients' physical strength and reduce their psychological stress (papers **III, IV**). Although appreciation for the environment offered external enabling of ability, the findings also revealed that nature helped them acknowledge their own existence, and they found it easier to connect with and find transpersonal relatedness to a supernatural power (papers **III, IV**). The findings revealed that if patients experienced something that suited their capability, something they found pleasurable and motivating, this *hobby* and *activity* created positive feelings and joy, and they practiced it over and over again.

**(c)** Other factors that impacted on the patients' external enabling of ability were revealed in their contact with health care, categorised into *health care organisation, health professionals' knowledge and experiences, and health professionals' attitudes*. The findings revealed that patients had a better feeling of health when the *health care organisation* successfully provided long-term, continuing access with individualised, tailored care from, e.g. physicians, dieticians, dentists, dental hygienists, and nurses (papers **I, II**). This corresponded to the findings revealed when patients experienced confidence in health care and turned over the medically responsibility to health professionals because of their own lack of medical knowledge (paper **IV**). *Health professionals' knowledge and experience* was an expectation, and the patients always assumed that health professionals were skilled, knowledgeable, effective, and updated on medical and technical issues (papers **I, II, IV**). It was understood

that the patient needed to be respected as a unique person and needed to be believed when telling their illness story. Contacts with health professionals could then facilitate improved health (papers **I, II, IV**). These contacts were named *health promoting contacts* and were mainly experienced during the treatment phase when patients had daily contact with specific, qualified health professionals (paper **II**). It was understood that kind and considerate treatment was invaluable in contacts with health professionals and enhanced a patient's sense of autonomy (papers **I, II**). It was obvious that patients wanted to remain as independent as possible. However, during acute life-threatening situations they had a sense of well-being despite their dependence, i.e. when health professionals cared for, checked, examined, and observed them (papers **I, II**). The findings revealed that *health professionals' attitudes* or behaviours, e.g. silent body language or outspoken views on mankind, were especially important for the patients' learning and confidence in performing self-care (paper **III**). In dealing with the patients' speech impairments it was important for health professionals to be attentive and have a humble attitude. Then, patients felt that co-operation and a practical working relationship were achievable (papers **I, II**). The patients wanted to be seen and respected as active persons. They wanted to meet health professionals that supported their health objectives and positive potential for health rather than focusing on the disease and related problems (paper **III**). The findings revealed that the patients' strengths, competencies, and health resources grew in the course of participating and co-operating with health professionals through mutual or individual initiatives (paper **I**). Also, the patients revealed that they were surprised to meet health professionals that showed solicitude and were available, engaged, respectful, confirming, and did more than expected (papers **I, II**).

## Experiences of hindrances to health and feelings of well-being

In the face of the patients' vulnerability and new life circumstances, accompanied by distressing illness experiences, the findings revealed how complicated it could be to set and attain goals for better health. In addition, it was understood that in human encounters, and especially in the dependant position of being a patient and seeking health care, people could feel that they had lost their power and self-control (papers **I, IV**). Consequently, the patients' could experience hindrances to health as a lack of ability to connect to his/her (1) *internal* and (2) *external enabling*.

### (1) Lack of ability to reach internal enabling

Some patients revealed a lack of ability to reach goals for health, due to their inability to connect to inner strength, and the findings revealed feelings of diminished strength of mind (papers **III, IV**). The findings also revealed a changed self-image that seemed to burden the patients with feelings of low self-esteem and decreased self-confidence. These shortcomings in self-directed support could also result in a self-depreciated sense of how other people viewed them, and they felt as if they were living in a compromised state (paper **IV**). The feeling of self-imposed incarceration was obstructed, giving rise to feelings of being taken hostage by health care. The findings also revealed that the patients' weakened self-worth interfered with their autonomy and performance, and they felt left out of treatment decisions, like a guinea pig (paper **IV**).

## (2) Lack of ability to reach external enabling

Hindrances in reaching external enabling were connected to the same factors and revealed a lack of support from **(a)** social networks, **(b)** contact with environment, **(c)** and health care.

**a)** Patients' diminished inner feeling of self could influence their social contacts and change their relationship to next of kin, thereby increasing isolation. In addition to the adverse physical and communicative impact of their illness, patients felt discomfort from being in situation that forced them to depend on others day and night (paper **IV**).

**b)** However, the findings also revealed feelings of insecurity caused by the gravity of illness that forced the patients to stay home alone, having little contact with nature. Patients revealed that they felt a necessity for restrictive living. Hence, in addition to the fatigue that diminished or stopped their involvement in hobbies and other activities, this created feelings of ill-health and powerlessness (paper **IV**).

**(c)** The same external factors could also be experienced as hindrances in enabling patients' contact with health care, and could also be categorised into *health care organisation, health professionals' knowledge and experiences, and health professionals' attitudes*. The findings revealed that *health care organisation* could be experienced as a barrier to patients' feelings of well-being, and the patients frequently revealed feelings of abandonment and lack of confidence in health care. When problems arose, the patients were often uncertain who to contact amongst the numerous health professionals (papers **I, II**). They felt lost and, due to their vulnerability, dared not ask questions. Moreover, they felt exhausted by the massive, impersonal, one-way information and other shortcomings in human encounters (papers **I, II, III, IV**). It was

understood that at times *health professionals* did not comprehend patients' feelings of vulnerability resulting from dependency on health care, and this insensitivity increased the patients' suffering and contradicted their feelings of health (papers **I**, **II**, **III**, **IV**). The findings revealed deficiencies in accessibility and continuity of health care. This, added to a sense of being caught in a permanent illness trajectory, compounded the patients' vulnerability and stress in life (paper **IV**). Contacts with health professionals that revealed hindrances against improving health were named *not health promoting contacts*, and were experienced predominantly before and after treatment (paper **II**). Still it was understood that the most important factor to patients was to be believed when expressing their illness story (paper **II**). If the patients were met by *attitudes* from *health professionals* of not being respected, or even listen to, it led them to search for attentive health professionals. Patients revealed being put off balance, i.e. less capacity to grasp health goals, when encountering unengaged or incompetent health professionals with paternalistic or superficial attitudes who seemed to lack respect for the individual behind the patient role. When patients worried about the imperfections in their body such encounters were often accompanied by feelings of not having their opinions valued (papers **II**, **IV**).

## Discussion

This thesis aimed to reach a deeper understanding of living with head and neck cancer (HNC) and to identify the experiences that patients felt promoted their health and well-being. The thesis also explores the patients' experiences of contact and care with health professionals and whether these encounters could increase their feelings of better health and well-being.

The findings concerned 35 individuals diagnosed with HNC, revealing their experiences of what they thought promoted their health and well-being and their opinions of what could enable them to increase control over and improve health. Their connection with *enabling*, i.e. providing someone with the ability or means to do something (Soanes & Stevenson, 2004) was important to their success in experiencing health and well-being and the process of taking control over a new life situation. This process of empowerment, i.e. the goal of health promotion (WHO, 1986), was an ongoing process of contacting and using their inner strength; their internal ability or skill to motivate action. Further, enabling was associated with external connection to environmental factors e.g. relationship to family/friends, health professionals, nature, hobbies, and activities that stimulated patients to engage in processes to move forward, believe in a future, and take command over everyday life.

The comprehensive understanding gained from 53 interviews with 35 purposefully selected patients (31 from Sweden and one from each of the other Nordic countries) revealed that living with HNC was like living on a virtual rollercoaster, but still having strong beliefs in the future. The patients experienced life as a constant series of ups and downs. On one hand, fighting day and night with HNC's life-threatening impact and the side-effects of the treatment or tumour growth, e.g. breathlessness, and bleeding. On the other hand, making it through the 'downs' helped the patients believe in the future, since it gave them an enhanced feeling of confidence in their ability to orient themselves towards health and self-empowerment. In a way this corresponds to Antonovsky (1987) research when he put forward that as long as there is breath of life in us, we are all to some degree healthy and we are always during our lifetimes moving between two extremes of ease and dis-ease on the health continuum.

Perhaps this interpretation of *life on a symbolic rollercoaster* is not exceptional and could be experienced by many people, with or without a sickness. Many people struggle with life-threatening diseases combined with treatment complications and an insecure future, e.g. people with diverse forms of cancer or other chronic diseases. For example, Brännström's (2007) research on living with severe chronic heart failure in palliative advanced home care was interpreted as life on a rollercoaster. However, the interpretations of Brännström's research and of the 35 patients that participated in my study are very divergent. Perhaps this difference can be attributed to the researchers' interests and perspectives, e.g. my research takes only a single perspective (the patients'), while Brännström's takes three perspectives (the patients', nurses', and close relatives'). Another important factor could be the researchers' perspectives (pathogenic or salutogenic) in interpreting the findings. Although the participants in this thesis had numerous physical symptoms and experienced many 'ups and downs' they tried (and often succeeded) to repress negative feelings to make life bearable. It appears that positive thinking was of central importance in helping the participants maintain a positive self-image and hope for the future. Positive attitudes might have originated from the willpower to fight the disease, or might have been a way to feel better. De Raevé (1997) describes positive thinking as a way to take responsibility for prevention of and recovery from cancer, i.e. one strategy to cope with cancer and its treatment. But positive thinking could also place another burden on the already afflicted person, i.e. if you think positive enough the cancer can be cured (cf. McCreadie et al., 2010). Being positive might be part of a process where patients actively seek meaningful and therapeutic interactions with health professionals, thereby gaining important knowledge (ibid.). Brännström (2007) revealed no interpretations about the patient's inner strength and capacity to take control

over the illness. She did, however, reveal the importance of support from relatives and health professionals.

For some of the patients living with HNC, the disease was understood to be on a permanent illness trajectory that changed their life into a state of physical, emotional, social and existential captivity. This translated into a difficult everyday life, especially highlighted by the findings showing their aloneness, even when cohabiting or having close relationship to next of kin and/or friends (paper **IV**). This corresponds to other research showing that patients on a cancer trajectory often experienced uncertainties, vulnerability, and isolation (Halldórsdóttir & Hamrin, 1997). In addition, HNC causes potentially life-threatening problems, e.g. involving respiration, nose bleeding, choking while eating and swallowing, and it also causes lifelong physical problems, e.g. altered communication and changed appearance (Ledeboer et al., 2005). However, no research was found that addressed the findings on patients' feelings on an altered relationship to their body, which confronting them with embarrassing behaviours, e.g. phlegm stagnation resulted in a need to repeatedly clear the throat and spit (papers **I**, **III**, **IV**). These problems appeared to have a huge impact on patients' entire everyday life and could correspond to Anderson & Franke's (2002) research on HNC's bodily impact that seemed to confront these patients' with both a psychosocial and existential struggle.

The findings stress the importance of meeting soul mates, since the patients experienced a substantial difference in talking to and receiving information and support from someone that had life experiences with this illness (papers **III**, **IV**). Perhaps because of the changes in their appearance, eating, and speaking, patients could need to meet others with experience of similar problems. If you experience something you have a deeper knowledge and understanding of the problem, e.g. changes in everyday life, and how different periods in the trajectory could be experienced. Trillin (1981) emphasised that having cancer signifies entering the land of the sick, where those from the land of the well could visit, but always leave. Birkhaug et al. (2002) claimed that active memberships in patient organisations improved patients' well-being, and perhaps these meetings could alleviate some of their loneliness and help regain power and control over everyday life. Still, as Mok et al. (2010) point out, there is no medication for alienation, loneliness, despair, meaninglessness, and fear of death. Hence, findings on patients' endeavours to find meaning in life through love, hope, confidence, and belief in the future, i.e. to reach the best possible well-being to achieve new life goals, were important (paper **IV**). Mok et al. (2010) also stressed that it was essential for the patients' emotional and spiritual well-being to meet health professionals that showed caring attitudes and delivered expert information with cheerfulness and kindness.

It was indispensable for patients to trust in their own strength and abilities of dialoguing with the inner self, i.e. internal enabling, which transformed and improved their self-esteem and enhanced their self-determination (papers **I**, **II**, **III**, **IV**).

HNC can cause discomfort and suffering since it is located in the body's most visible area. This could either enhance personal growth or damage or destroy self-esteem (Ledeboer et al. 2005). Lindenfield (1996) suggested that if a person believes that he/she is worthless or ugly it could generate negative feelings and depression. Mok et al. (2004) asserted that if health professionals focus on resources rather than health deficits this could more effectively influence the individuals' thoughts and attitudes in a positive way. Feber (2000) highlighted coaching in intrapersonal skills as a means of promoting optimum health and well-being for the individual with HNC. Dropkin (1999) showed that self-care could be beneficial and reduce anxiety in disfigured persons since it helps patients find their true self and adapt to their new body image. This corresponds to research by Turpin et al. (2009) showing that patients with HNC went through an active process to retain a positive sense of self when the illness impact altered their relationship to their own body.

It was as the individuals improved their sense of self-worth when they took control over their new life situation, and this helped them break many years of lifestyle habits, e.g. smoking and alcohol consumption (paper **III**). Adopting new lifestyle habits required inner strength and will, but was not an easy task (cf. Nygren et al., 2007). The findings revealed that patients' inner strength potentially gave them a greater will to live, to manage their situation, and to be open to looking forward and continuing their life. It could be valuable for health professionals to draw on these findings when following public health advice (NIPH, 2005), e.g. to start smoking cessation programmes in HNC care (Sharp & Tishelman, 2005), and begin to find out if patients are motivated to make lifestyle changes. These findings also correspond to the research of Mok et al. (2004) regarding patients' motivational process, process of seeking mastery, and transformation of thoughts. The findings also revealed that the patients' often used their power of mind when meditating and praying (papers **III**, **IV**). Meditation and/or prayer, i.e. self-transcendence are shown to be helpful in drawing on one's own strength and health resources (Teixeira, 2008). Some patients expressed high self-confidence in spirituality and being present in the here and now, with no fear of dying – hence, finding meaning in life by thinking that death was a transition to another state of being (paper **IV**). Acceptance of death as a process in life, and letting go, corresponds to the research of Mok et al. (2010) claiming that inner spiritual well-being is attained from having faith and being aware of possibilities in life and after death. The findings revealed that integration of spiritual and personal beliefs lead to peacefulness, harmony,

and spiritual growth. In addition, it is known that patients with HNC often use complementary and alternative methods, such as spiritual therapies, herbs and vitamins, physical therapies, and body/mind therapies (Molassiotis et al., 2006). Frenkel et al. (2008) advocate integrating these methods into health care and advise health professionals to engage with, support, and give appropriate advice to patients wanting to complement their medical treatment with such alternatives.

The findings revealed that some patients found a glass of wine or beer to be beneficial and relaxing (paper **III**). This correspond to Allison's (2002) research showing that using (as opposed to abusing) wine during recovery can lead to better physical and role functioning, less fatigue, and fewer feelings of illness. This way of caring for and encountering patients with HNC requires health professionals to be attentive, listen to and respect patients – and to relinquish some of their own power to trust in, and dare to support, patients' actions and wishes.

Good interpersonal relationships and emotional support, i.e. external enablers such as next of kin or friends, were essential. It was understood to be vital to have someone to talk to, day and night – perhaps particularly vital when patients experienced new illness and acute, life-threatening problems in everyday life (papers **III**, **IV**). Again, this corresponds to the research of Mok et al. (2010) on the necessity for patients to have well functioning relationships and connection with next of kin and friends. However, research also shows that the relationship between two individuals could be experienced as difficult, due to a dependency on support that one might need from the other (cf. Cutrona, 1996). The findings also support this, revealing strained relationships and changed life situations for some of the participants and their family as an entity. It could be altered role function at home, and some participants felt rejection from next of kin. Vickery et al. (2003) highlight that partners could report greater distress than the sick person they care for. Additionally, the findings revealed transformed emotional and sexual relationships, particularly amongst the women interviewed for this thesis (papers **III**, **IV**). Manne and Badr (2009) confirm that relationships and intimacy seem to be more important for women to discuss. These problems with relationships might relate to the patients' problems with phlegm production or mouth odour, which both parties could experience as unpleasant. Millsopp et al. (2006) stressed that this cancer also could be experienced as more traumatic than other cancers because of the visible disfigurement involved. The findings revealed high psychological stress and vulnerability in the patients, partly because of how they viewed the life situation of their next of kin. The patients were understood to have a difficult everyday life, and it was essential for them to take an active role, to be responsible for their own self-care, and seek support from next of kin or good friends when

needed (papers **II**, **III**, **IV**). Humphris (2008) discussed the need for continuing support from psychologists. The findings also presented various confirmations on the importance of long-term support for next of kin (cf. Wright & Leahey, 2005). Co-operative care, which seems to alleviate fear by providing self-care education in a home setting, appears to be a valuable approach. This approach has been shown to conserve health resources and improve and facilitate communication amongst the family and health professionals involved in care (McLane et al., 2003). In recent decades, interest has been growing in psycho-oncology and emotional well-being for patients and their next of kin (Hodges & Humphris, 2009). Training courses for patients and next of kin, e.g. on learning to live with cancer, seemed to be valuable for all who took part in them and were reported to help empower patients to take greater control over everyday life (papers **I**, **III**, **IV**). The courses were based on a teaching-learning process with an interactive and systematic bottom-up approach (Grahm et al., 1999) that could help patients and their next of kin choose topics they wanted to discuss, ultimately empowering and supporting them in achieving defined health goals. The findings also revealed the patients' eagerness to learn and preserve independence and autonomy and to practice self-care (papers **I**, **II**, **III**, **IV**). This corresponds to research by Mok et al. (2004) suggesting that when patients owned knowledge and skills and practice self-care, they could accept the illness. In turn, this could lead to feelings of better health and well-being.

All the participants narrate that they received strength and felt good when being outdoors and following the changes in nature, i.e. also an external enabler. Nurturing plants to survive and blossom also gave patients a sense of hope for the future; to be alive despite their sickness (papers **II**, **IV**). Ottosson and Grahm (2005) emphasise the link between nature, health, and healing. In health services, this means taking responsibility for creating a healthy care environment for everyone who visits a care facility or is hospitalised (WHO, 2004). Creating an atmosphere that is pleasing for the eyes, and combining this with easy access or views to parks and green spaces, enhances everyone's well-being; patients, next of kin, and health professionals. In addition, Maller et al. (2005) assert that nature can be viewed as an unused public health resource since it has the potential to increase people's sense of well-being. Hence, it appears that parks and natural areas are potential 'gold mines' for a population's health promotion.

Hobbies and cultural activities suited to the situation are other external enablers, and by practising these activities over and over again the patients experienced control and power over everyday life (papers **I**, **III**, **IV**). This corresponds to other research showing, e.g. that art therapy could decrease anxiety and facilitate recovery and power over everyday life for women with breast cancer (Oster et al., 2006). In addition, the use of music in health care is known to promote

feelings of power, enhance effects of analgesics, and decrease pain, anxiety, and depression (cf. Siedliecki & Good, 2006).

Working relationships with respectful and competent health professionals could encourage a patient's activity, participation, co-operation, and self-care. It was also understood that positive human encounters could contribute towards counterbalancing the often unequal position that patients sometimes felt in health care. This was named *health promoting activity* (paper **I**) or *health promoting contact* (paper **II**). In this context, the patients experienced health professionals to be available, engaged, respectful, and validating and to express knowledge, competence, solicitude, and understanding. Research by Ong et al. (2000) confirmed that a good interpersonal relationship between the patient and health professionals could be viewed as both "means and end" in an interaction/contact. These health promoting contacts could, to a certain extent, correspond to research on supportive clinics that could help patients with emotional and practical needs (Larsson et al., 2007; Wiederholt et al., 2007; Wells et al., 2008). Nevertheless, the findings showed that, especially before and after treatment, the patients felt abandoned and lost amongst all the members in the multidisciplinary team that were involved in their care (papers **II**, **IV**). These findings suggest that the current healthcare organisation is characterised by large-scale production that is function oriented – not a patient-process-oriented organisation. It seems that a healthcare organisation with supportive clinics must be developed and be accessible 24 hours a day. Care needs to focus on the unique patient and be designed as individually tailored, patient-centred care, throughout the lengthy trajectory of illness (cf. IOM, 2000). Lee et al. (2008) tested the IOM recommendations, but found a need for development of interpersonal communication and practise-based learning for health professionals working in the HNC care context.

To improve the organisation of HNC care, it should develop in collaboration with patient organisations (Birkhaug et al., 2002), health professionals (SSF, 2008, SBU, 1999), and policy makers (NPH, 2009). Patient organisations are vital because of their potential influence as the voice for an entire group of patients. Such organisations can raise demands on behalf of their members, who may have less of an opportunity to speak up in society due to the impact of the illness on their ability to communicate (Birkhaug et al., 2002).

It is, however, known that these patients often have long-lasting and slowly progressing health problems (Bjordal et al., 2001). In addition, the findings showed a lack of individualised, tailored care from a salutogenic perspective. It was also understood that some patients experienced discouraging obstacles against better health and feelings of well-being, and these vulnerabilities seemed to cause low self-esteem and low self-performance (papers **III**, **IV**). This

highlights a) the need for easy access to care with a salutogenic focus and to long-term psychological rehabilitation and b) the need for good contact with health professionals who follow patients throughout the entire course of their illness trajectory. Rehabilitation services should also involve any next of kin engaged in a patient's everyday life and care. Fillion et al. (2006) proposed using an oncology patient navigator to ensure that patients' interests and concerns remain in forefront, along with values that empower the patient and humanise care. Such navigators have been shown to enhance the support for HNC patients throughout treatment, recovery, or cancer progression and death (Fillion et al., 2009).

The findings also indicated that the patients experienced many *not health promoting contacts* (paper II) and a *lack of health promoting activities* (paper I). Such encounters could lead to feelings of ill-health and powerlessness. Some health professionals seemed to be insensitive to the patients' vulnerabilities and did not listen to or respect patients' opinions, reflecting a superficial and paternalistic view of mankind (papers I, II, IV). These findings correspond to the research by Halldórsdóttir & Hamrin (1997) about caring versus uncaring. When patients perceived that nurses were incompetent in some way, (e.g. nonchalant towards the patient as a person, or uninterested in the patient's competence) this created an obstacle in the patients' well-being and recovery. Findings by Wilkinson et al. (2003) emphasise that professionals working in health care, especially in cancer care, must have special skills such as being an attentive listener, i.e. open for patients' questions and narratives.

One challenge could involve being responsive to behaviour and psychosocial responses to bad news and delivering up-dated information in a series of processes along the cancer trajectory (Tobin & Begley, 2008). Newell et al. (2004) confirm this and emphasise information, support, and advice all the way through the postoperative period after a surgical procedure. Leydon (2008) points out that patients want health professionals to openly share bad news and uncertain information, but to do it with sensitivity. A recommend approach was to follow up uncertain or bad news with slightly better information to avoid diminishing opportunities for hope or future optimism (ibid.).

Patients experienced many hindrances in accessing health services, particularly the first contact with health professionals in the front line of care was problematic, and often the patients felt they were not believed when telling their illness history (paper II). Carlson et al. (2005) highlight the dynamic and context specific nature of communication, and research shows the complex communication problems that patients with HNC can experience (Happ et al., 2004). Semple and McGowan (2002) stress the importance for health professionals to check that the information supplied has been understood and to

be ready to provide further information if necessary. Patients with HNC need tailored information and clearly written information in a readable form and without jargon, since suitable information could promote collaborative decisions (ibid.). Patients also experienced being in a disadvantaged position due to their vulnerability and dependence when seeking care (papers **I**, **II**). Research confirms the inequity of power in health care, due to the patient's dependency, and this could be an obstacle in interpersonal relationships between patients and health professionals (Ong et al., 2000).

Thorne et al. (2008) discuss how ineffective communication can lead to delay in seeking care, failure to access appropriate care, and early withdrawal from treatment. Research has shown that some resilient HNC patients exhibited a profound reluctance to ask for help, despite extensive physical and emotional trauma (Wells, 1998). This could correspond to the patients that choose the wellness-in-the-foreground perspective, as described in the Perspectives Model of Chronic Illness, where some patients have trouble receiving the services or the attention they need (Thorne & Paterson, 1998; Paterson, 2001). Then patients struggle to maintain a positive attitude, keep active and independent, and try to live everyday life as normally as possible (cf. Kvåle, 2007). These strategies aim to maintain hope and to distance one's self from certain aspects of authenticity. However, this disaffection should not be confused with rejection and non-acceptance; it entails strategies to maintain some sort of normality (Paterson, 2003). Health professionals are accustomed to working with the-illness-in-foreground perspective and are skilled in supporting patients with information and teaching them how to manage their illness (papers **I**, **II**, **III**, **IV**). HNC patients undergoing treatment wanted as much information as possible, both good and bad, especially about the treatment and its side-effects (Semple & McGowan, 2002). On the other hand, patients had expressed being overloaded with information they do not understand (ibid.). Research by Thorne et al. (2006) revealed that health professionals at times provide patients with 'hard-core' information as part of their professional duty and not as a result of a sensitive dialogue.

The-illness-in-foreground perspective was understood to be good in the context of this thesis if patients had the strength and motivation to learn. However, some health professionals could find it puzzling when a patient talks of well-being while having a multitude of problems. The Shifting Perspectives Models of Chronic Illness has elements of both the wellness and the illness perspective, and represents the patients' viewpoints, perceptions, hope, attitudes, and life experiences. Hence, it appears to be a valuable tool in this care context. It enables health professionals to understand the patients' perspective at any given time and make suitable care and support available to patients with either perspective (Paterson, 2001).

It was understood that some patients experienced unemployment as distressing (paper **IV**) while others, in contrast, felt threatened by their employer and felt forced to continue working (paper **IV**). It is well known that loss of occupational identity can be a source of significant anxiety and depression in everyday life (cf. Peteet, 2000). Research has shown that post-treatment patients frequently experienced becoming employed because of their unique problems regarding, e.g. eating, speaking, pain, fatigue, and appearance (Buckwalter et al., 2007). Liu (2008) stresses that thoughtfulness must be exercised when supporting patients to continue working, and they need rehabilitation that is comprehensive and takes into account their contextual situation and burden of everyday life (Tschiesner et al., 2009). The findings highlight the need for health professionals to deepen their understanding of the patients' everyday life with HNC in relation to health, illness, and suffering (papers **I, II, II, IV**). A vital factor for patients with chronic diseases is to have a well functioning everyday life (cf. Kickbusch, 2007).

The patients experienced social and economic strains (paper **IV**). Semple et al. (2008) addressed the increased cost of living with HNC, e.g. medicine, special diets, and lengthy treatment periods with related travel expenses, and inability to work. The findings also revealed long lasting side effects of treatment, e.g. jaw- and tooth-related pain (papers **I, II, IV**). Adell et al. (2008) confirmed that some of the former HNC patients could never be rehabilitated to overcome the inconveniences in the jaw and teeth, and in those who could, it took years to restore dentition. The findings in this thesis mirror the long-term struggle with distress, pain, and social and economic hardship in the patients' everyday life, and reflect a demand for public health and psychosocial interest for this group of patients. In recent years, health professionals in Sweden have raised criticism towards the social system and the allowances for patients having different types of cancer (SWEDPOS [Swedish Society for Psychosocial Oncology], 2010). This association advocates that society and health services need to support cancer patients and their next of kin with psychosocial care and rehabilitation of good and equal quality at all stages of disease and survivorship. Their work appears to offer a vital and necessary forum for health professionals in HNC care to raise their voices more often and to be more involved in health and social policy decisions.

## Methodological considerations

A qualitative design was chosen to reach a deeper understanding of living with HNC and to identify the experiences that patients felt promoted their health and well-being. The study design also revealed their experiences of care and contact with health professionals. This design was judged to be the most accurate means

to describe and explore the patients' subjective truth and reality of their own life experiences.

The four studies were based partly on different concepts related to health promotion. This could be viewed as a threat to the internal conceptual validity of the research as a whole. On the other hand, however, this conceptual variety reveals the versatility of health promotion strategies and points of departure. It also reveals how my own way of thinking about health promotion developed during the research. My transformed view of the concept could be attributed in part to the many years that elapsed between conducting the first study and conducting the later studies. Another possible factor could be that society changed during this period, as did the concept of health promotion. Nevertheless, my approach towards the central concept of health promotion remained consistent with several of the basic principles, e.g. participation, partnership, equity, and inter-sector cooperation, but not always with others, e.g. holism and empowerment.

During the first study my views towards the patients were quite objectified, i.e. a person "within" a specified form and stage of HNC (e.g. a patient with stage-4 oropharynx cancer). This was accompanied by my 'mental image' as a nurse of these patients' common problems and needs. My standpoint on the concept of health promotion came from this traditional biomedical and pathogenic view, i.e. nurses should inform and educate patients about risk factors for acquiring diseases and should advise patients to change to a healthier lifestyle. For instance, see the suggestions in paper I; that the nurses could identify and focus on those individuals who need to alter their lifestyle.

However, my understanding about everyday life with HNC and individuals' inherent capacity grew. Hence, in the later studies, my views on the concept health promotion changed, centring more on the individual's point of view and experience of living with HNC. As a result, the concept shifted towards a more subjective-oriented understanding of the need to focus on the affected individuals' own experiences of what promoted health and well-being. This represents a shift from the traditional "top-down" approach to a "bottom-up" approach integrating the individual's own capacity to take control and become empowered. When health professionals view the patient as a person – an expert on his/her own situation and co-producer of his/her own health – it strengthens the patient's confidence in drawing on their own resources to improve their personal health and well-being.

The studies in the thesis focused on 35 patients with HNC. Data were collected via individual, audio-taped, semi-structured, qualitative interviews. This semi-structured interview approach seemed appropriate since the aims were to

identify areas that each participant would cover, e.g. what promotes health in everyday life or what promotes health in contacts with health professionals. However, the questions were open-ended so participants could speak without restrictions about these topics and could also initiate new topics.

Different methods and analyses, all sensitive to human experiences, were used to interpret the data. Paper **I** used the critical incident technique (Flanagan, 1954); paper **II** used thematic qualitative content analysis (Baxter, 1991); paper **III** used latent qualitative content analysis (Berg, 2004); and paper **IV** used interpretative descriptive analysis (Thorne et al., 1997; Thorne et al., 2004).

Despite some differences between the four analytical methods used, they followed basically the same approach throughout the studies. First, the researcher(s) read the full text of each interview to determine the most important aspects of the phenomenon under the investigation. Second, the researcher(s) developed a more structured thematic analysis of every interview when searching for meaning units/codes in sub theme. Finally, the researcher(s) examined the sub themes in the context of more superior themes, all at different levels of interpretation.

Two variations of qualitative content analyses method were used in the second phase of collecting data (papers **II**, **III**), and steps were taken to assure reliability of the data collection, i.e. after three test interviews a new semi-constructed interview guide was developed to cover questions addressing topics in both papers. The thematic content analysis (Baxter, 1991) used in paper **II** is obviously similar to the latent content analyses (Berg, 2004) used in paper **III**. In both analyses the approach involves searching for patterns or themes, i.e. the deep structural meaning conveyed by the message. As a result, the findings in those articles appear to fall within the same interpretation level.

In the final study, the interpretative descriptive analysis (Thorne et al., 1997, 2004) was somewhat different since it started with a pre-analytic understanding. The difference between the pre-analytic understanding and my findings was that the patients' experiences of what it meant for them personally were complex and not comparable since their everyday life was now so different. One weakness could be that my discussion of the findings is based on the similarities instead of the different individual themes and sub themes for the unique six patients.

Further to ensure the quality of the findings, methodological considerations have been considered in terms of the five criteria for trustworthiness: credibility, dependability, transferability, confirmability, and authenticity (Lincoln & Guba 1985; Guba & Lincoln, 1994). The central aspect is to confirm that the findings truthfully mirror the experiences and viewpoints of the participants, rather than perceptions of the researchers (Polit & Beck, 2008). Lincoln & Guba

(1985) highlight that if credibility is recognized, consequently so will dependability. Therefore, the aspects undertaken to guarantee creditability also serve to guarantee dependability.

*Credibility* refers to confidence in the data and their interpretation. The strength lies in the process of purposively selecting the patients – in consultation with medical and nursing staff involved in their care – and following the criteria, i.e. patients' with diverse HNC diagnoses, stages, and treatment. Although variation in socio-demographics was not the most important criterion, it was important to find patients with the willingness and interest to communicate and verbalise their lived experiences (cf. Polit & Beck, 2008). Paper I makes reference to strategically chosen patients, but it also conveys a purposive selection since the interviewer worked in one hospital and therefore could ask some patients if they would participate. A limitation could be the unbalanced sample in paper I (i.e. 17 individuals from Sweden and one from each of the other four Nordic countries). Although the purpose was not to generalise or compare the findings between countries, more participants from the same country might have given more contextual data. In view of the research design, the data are not sufficient to make generalisations based on the findings.

The patients' gender and age differences are in line with data showing that HNC is two to three times more frequent in men and most common in the group >50 years of age (Parkin et al., 2005). A weakness could be that although 54 persons were invited, 19 did not agree to participate. It indicates that many of the individuals did not want to participate. Nevertheless, those who did were eager to contribute information about their experiences, and they provided rich descriptions. It should be noted that three of the participants heard of the studies and asked to participate. They contacted a nurse at the ward on their own initiative (Paper II, III, IV). These participants all had severe speech difficulties because of surgery and tumour growth, yet they gave concise information and lengthy interviews.

The non participants were mainly men and younger people. Hence, a weakness could be that the findings may not reveal the experiences of younger people and people that did not match the selection criteria, e.g. confused or cognitive disable patients that could not communicate their experiences.

Communication between the interviewer and the interviewee during the interview situation may have influenced the quality of the data; since it is the researchers themselves that serve as data-gathering and analytic instruments in qualitative studies (Polkinghorne, 2006). However, bias could arise when gathering data with help of critical incident techniques as the interaction between interviewer and interviewee could be close and intense (Flanagan,

1954). To avoid this, the questions posed were as open as possible. The participants could talk freely about the topic, and the interviewer thoughtfully went back and forth between the questions in the guide (paper I, page 206).

Strength was that every interview were rich in content, quality, and meaning i.e. they were experienced as open, profound, and emotionally charged, and no problems were observed regarding the request to audio tape the interviews. The patients' showed an eagerness to contribute to the research, and together with the relaxed atmosphere during the interviews this fulfilled the criterion of a trusting and confidential relationship (cf. Polit & Beck, 2008). The interviewer was familiar with the care context, and her interviewing skills progressively expanded as she conducted more interviews. This was evident from the interview transcripts. In the first study, she spoke and asked questions frequently, but in the latter studies the patient's voice dominated, and the patient was often first to break the silence.

The patients always chose the interview site, and most interviews were performed in the home. In-hospital interviews with inpatients were often shorter. On the whole, interviews conducted in hospital were shorter, but more convenient for outpatients who wanted to combine the interview with their hospital appointment.

Since patients' speech problems could potentially jeopardise understanding, at times the questions were reformulated to achieve a shared understanding of the core response to these questions and avoid misinterpretation or the possibility that patients' answered in a way they thought might please the interviewer.

Nine of the patients did not have Swedish as their native language. These patients received a written inquiry in their own language (Nordic language), and their interviews could include English words, notes of non-verbal interaction, body language, and help from next of kin. Verbal input from next of kin was taken into account only if the patient asked them to explain a word and gave a nod of approval. However, these small contributions from next of kin seemed to help; they not only elucidated and endorsed information, they also confronted the patient to talk, often about things not mentioned previously.

Although the interview questions were asked in positive sentences, e.g. what they felt promoted their health, the patients' answers occasionally revealed negative experiences (papers I, II). It seemed, if we wanted to understand or know that something was good then we needed to confront it with the opposite, and thereby reach a deeper understanding of the subject under study (cf. Halldórsdóttir & Hamrin, 1997).

Other researchers have used this approach when obtaining both positive and negative findings (cf. Söderberg, 1999). Looking at my findings in paper I (page 208) and the category the nurse showed personal consideration and the subcategory the nurse showed empathy. The positive form conveyed that the patient experienced the nurse as attentive, and she respected him: *the nurse was so calm and collected and sympathetic*. The negative form conveyed that the patient experienced that the nurses lowered his self-esteem by patronising his integrity; *the nurse was too good-natured, she felt sorry for me, I didn't like it*. In paper II (page 266) the positive form in the theme receiving individualised, tailored care conveys experiences of being confirmed and feeling secure; *she called the dentist to prescribe medication for thrush ... I felt that I was well taken care of*. The negative form conveys the patient's experiences of being abandoned because no health professional wanted to take responsibility for their care; *they just remit patients from one place to another*.

The purposeful sampling of participants that had the eagerness and interest to verbalise their lived experiences yielded rich interviews, and the participants appeared to feel safe and comfortable in revealing their often negative experiences. Polit and Beck (2008) emphasise that when researchers have a sense of what they need to know, then the use of purposive sampling could strengthen a comprehensive understanding of a phenomenon. By searching for disconfirming evidence and competing explanations the researcher can challenge a categorisation or explanation (ibid.).

The value of repeating the interviews after a time was immense since the interviewer's understanding of the patients' everyday life grew with this extended relationship (paper IV). Further, a longitudinal approach gives you an idea about the participants' experiences over time and what it could mean for them in the process of healing, learning, and continued empowerment. It allows the researcher to revisit issues and discuss new areas that have emerged from the data, and also allows the participants to discuss areas they may have forgotten or decided to withhold during previous interviews (Polit & Beck, 2008).

*Dependability* concerns the stability of data over time and conditions, and was assured by using semi-structured guides and the same interviewer to conduct and transcribe all interviews verbatim. The verbatim transcripts allowed the researcher to remain close to the content of the interviews, and thereby ensure trustworthy and dependable interpretation. Different qualitative analyses were chosen because of the richness and profoundness of the text, making it possible to interpret the data on different levels (Burnard, 1995). Interpretation was an ongoing process that began already when the patients described their everyday life during the interview, and during the process they began to see and narrate new connections, free of interpretation by the researcher (cf. Kvale, 1996). In a

way, the interviewer condensed and interpreted what the patient said and then transmitted the meaning back, especially during probing. This also took place during transcription when a new cognitive interpretation emerged.

*Confirmability* refers to objectivity and was assured when analyses and interpretations were checked and discussed on a repeated basis with supervisors and in seminar groups with researchers. Confirmability implies that procedures were followed to ensure that the findings are rooted in the data and are not resting on insufficient analysis or preconceived assumptions. A potential limitation in paper I is the considerable overlap between categories, and the analysis could have been more rigorous.

However, all over the studies transparency and credibility enable readers to be “co-examiners” in gaining insight from analysing the patients’ quotations and arriving at different interpretations. Sandelowski (1994) discussed whether quotations should preserve every element of participants’ expressions, or be “cleaned up”, e.g. to eliminate grammatical errors. In this thesis, the patients’ quotations have been translated into English, but presented as their own choice of wording. A few minor revisions in grammar and vocabulary improved readability.

*Transferability* refers to the extent to which qualitative findings can be transferred or applied to other settings or groups (Lincoln & Guba, 1985). Yet it could be considered successful if patients with HNC, and health professionals working in this care context, recognise the descriptions and interpretations as credible. However, the core question in transferability is whether it is logical to carry out the innovation in a new practice setting. If some aspects of the settings contrast with the innovation, e.g. regarding philosophy, clients, personnel, or administrative structure, then it might not be sensible to try to apply the innovation (Polit & Beck, 2008).

Reasonably, transferability could be considered successful if people with cancer or neurological diseases, and who have similar severe communication and swallowing difficulties, could recognise the descriptions and interpretations as their own.

An important factor in promoting transferability is the quantity of information the researcher presents about the context of their studies. Kvale (1996) stated that a post-modern shift towards the search for general knowledge, and the individually unique, is being replaced by the importance of the heterogeneity and contextuality of knowledge. ‘Thick description’ refers to a rich and thorough description of the research settings, performance, and approach (Polit & Beck, 2008). Perhaps the contextual descriptions are thick enough for the

purposes of this thesis, and consequently could contribute to the reader's capability to assess whether findings would be applicable to other groups or contexts.

Transferability is analogous to generalisability. Naturalistic generalisation rests on personal experiences and derives from tacit knowledge of how things are and leads to expectations rather than formal predictions (Kvale, 1996). The findings show that participants' experiences and many quotations and interpretations of the findings are generally applicable to everyone, regardless of having HNC, e.g. the importance of emotional support from family and friends, and the importance of nature and culture in health. Analytic generalisation involves reasoned judgement about the extent to which findings from a study can be used as a guide to what might occur in another situation, and is based on similarities and differences of the two situations (Kvale, 1996). However, how much should the researcher formalise and argue generalisations, or could this be left to the reader (ibid.)? Kvale (1996) put forward Freud's therapeutic case stories as examples for reader generalisation, since Freud's descriptions and analyses are so colourful and persuasive that readers today still generalise many of the findings to modern cases.

*Authenticity* refers to the extent to which qualitative researchers honestly and truly show a variety of diverse realities in analysing and interpreting their data (Guba & Lincoln, 1994; Polit & Beck, 2008). This was assured since many of the findings and interpretations convey diverse shades of feeling in reference to patients' experiences and what it means to live with HNC. In many ways, the text invites readers into a vicarious experience of the lives being described, and enables readers to expand their sensitivity to the issues being depicted. Thereby, perhaps the reader can reach a deeper understanding of the patient's life, e.g. when reading quotations that contain non-verbal sounds (such as clearing the throat, spitting, hoarseness, or deep sighs) that could also mirror their own ill-health mood or feelings.

How people remember things could present a potential weakness of the studies. For participants in paper I, the time span from diagnosis to interview varied from 4 months to 14 years. Being stricken with cancer is an extremely traumatic experience accompanied by feelings that your whole existence is threatened (Carnevali, 1990). It is known that memory can change, but people always remember the critical incidents that occur (cf. Christianson, 1994). Flanagan (1954) asserted that the authenticity of data collected via the critical incident technique is high since participants narrate real, critical, events from life. Research shows that it is easier to remember negative incidents since often they are experienced as more intense and distinct than positive incidents (cf. Christianson, 1994).

# Conclusions

The aims of this thesis has been to reach a deeper understanding of living with head and neck cancer and to identify the experiences that patients felt promoted their health and well-being. It further conveys the patients' experiences of care and contact with health professionals, and examines whether these encounters could increase patients' feelings of better health and well-being.

- The deeper understanding of 35 patients' everyday life with HNC was expressed as living on a virtual rollercoaster, with many 'ups and downs', i.e. interpreted as living in captivity, day and night, because of the symptoms. However, when searching and finding inner strength, patients could experience better health and well-being, and this could generate strong beliefs in the future.
- The patients' inner strength potentially enhanced their will to live, to handle their situation, and to be open towards continuing with a changed life.
- Emotional support and good interpersonal relationships with next of kin was important, 24 hours a day, i.e. someone who could ameliorate the 'downs' and support the 'ups'. Other findings reflected the concern that patients have for the strained life situation of their loved ones, and the changes in emotional and sexual relationships experienced by the women interviewed.
- The patients' gained a sense of strength not only from nature, but also from hobbies and activities that enhanced their control and power over everyday life.
- Some patients experienced vulnerability and psychological stress, e.g. due to changed appearance, transformed eating and speaking ability, and the inconvenience of being in a dependent position.
- Some patients' felt that barriers hindered their access to health care. In particular, they found it difficult to make initial contact with health professionals working on the front line. An important finding in this context is that many of the patients felt they were not being respected or believed when telling their illness history.
- The patients' had feelings of exposure and vulnerability in encounters with health professionals. Health professionals' views of mankind, roles, and behaviours (e.g. body language) could either strengthen or weaken the patients' health and well-being. The findings correspond to those from other cancer research.
- The patients' had different strength to handle their altered life situations. However, the findings highlight that nearly every patient felt, at times,

lost and abandoned in health care during their long-term illness trajectory, especially before and after the treatment phase.

- Participation in patient organisations and courses (e.g. learning to live with cancer) was found to be valuable in lessening the patients' isolation.
- Learning and practising self-care seemed to lessen patients' dependency and increase their autonomy and self-worth.

## Implications for health promotion

The findings seem to confirm that health promotion is not something that is done *for* or *to* people; it is done *with* people, either as individuals or in groups. This corresponds with the basic principles in health promotion that is participation, partnership, empowerment, equity, holism, inter-sector cooperation, sustainability, and the use of multi-strategy approaches (cf. Nutbeam, 1998). These principles are regularly updated, since health is shaped by individual factors and the physical, social, economic, and political contexts in which people live. For example, needs assessment, evidence-based health promotion, and self-efficacy are new terms added to the mix (Smith et al., 2006). Beliefs in the latter, i.e. self-efficacy, determine how people feel, think, motivate themselves, and behave. In other words, it is the effort people expend and how long they persist in the face of disadvantage and adversity (ibid.).

In health care, patients need easy access, coordination, continuity, support from trained professionals and psychosocial rehabilitation in a patient-centred organisation. Supportive clinics could give patients, and their next of kin, long-term emotional, psychological, and practical support throughout the life-threatening and lengthy illness trajectory of HNC. Positive human encounters could help counterbalance the patients' unequal position in health care and strengthen patients' activity, participation, and co-operation, e.g. in smoking or alcohol cessation.

Maybe health care and health professionals need to place greater focus on salutogenic approaches, and receive further education in the bottom-up approach that starts from the patient's individual strengths and health resources. Such an approach would put patients in a better position to choose what they want to discuss and share, and ultimately could help empower them to achieve their defined health goals. The Shifting Perspectives Model of Chronic Illness could be useful to implement and evaluate in this context since the model seems to be suitable because of its elements of both the wellness and illness perspectives.

The findings could indicate that there is a need of greater support for the more vulnerable patients who live alone without nearby next of kin or friends and who experience severe emotional and existential confinement. Patient organisations that give a voice to this group of patients in society also need to be supported.

There appears to be a need to improve communication strategies and devices to facilitate patients' contact with the care system. Such strategies would include continuing education in communication for health professionals working with HNC care. Co-operation needs to improve between patient organisations, health professionals, and politicians in efforts to enhance economic, social, and health security. This includes support to help patients continue working and to meet needs for long-term rehabilitation.

Health care services need to take a greater interest in making cultural activities, arts, music, libraries, cafés, etc accessible to patients. Greater interest and action is needed to create healthy care environments for everyone who visits a care facility or is hospitalised. This includes easy access and comprehensive planning that takes into account secluded, quiet, relaxing rooms and views of parks and green spaces for patients and their next of kin.

## Further research

Health and health promotion is an integral part of nursing (SSF, 2008), and the findings in this thesis could be valuable in nursing and oncology practice; in rehabilitation and in palliative care. Conceivably these findings could be a starting point for further research in this important and demanding field. More qualitative studies could be done in this area to heighten awareness and create a dialogue about the concept of health promotion in HNC. For example more research needs to address the salutogenic factors that promote feelings of better health and well-being and generate strength and power for patients in a vulnerable and dependent position. More research is needed to explore whether spiritual growth promotes feelings of better health and well-being in people with HNC.

Research should focus on the next of kin's perspectives on what promotes health and well-being and what gives them strength in their 24-hour emotional support. Further gender research needs to investigate emotional and sexual relationships between couples, especially from the woman's perspective. Additional research from the perspective of health professionals should investigate what promotes their health and well-being and what gives them strength and power in their daily work as they encounter HNC patients and the next of kin.

Further research into new technologies and specific communicative devices in this care context could facilitate patients' contacts with others. Also, the working situation of patients and the impact of long-term, post-treatment side effects, e.g. eating and communication problems need further scientific investigation.

More quantitative studies could be done when testing hypothesis for example: Is there an association between patients with HNC that have experienced better health and well-being and being treated by nurses trained in bottom up approaches. However, an important issue is how we as researcher might influence health professionals to implement valuable research results in practical settings qualitative or quantitative. For example by applying in clinical practice the knowledge gained from evidence-based research into clinical health practice such as the Sense of Coherence studies (Langius et al., 1992, Antonovsky, 1996) and Quality of life studies (Aarstad et al., 2007, Rogers et al., 2008, Rogers et al., 2009).

# Svensk sammanfattning/Swedish summary

## Att leva med huvud- och halscancer: främjande av hälsa och välbefinnande i vardagslivet

Kroniska sjukdomstillstånd såsom cancer räknas numera till de stora folksjukdomarna och för personer med huvud – och halscancer är vikten av ett fungerande vardagsliv en ofta förbisedd folkhälsoutmaning. Avhandlingens övergripande syfte var att få en djupare förståelse för vad som främjar hälsa och välbefinnande i vardagslivet för personer med huvud – och halscancer. Ytterligare ett syfte var att utröna huruvida vården och vårdpersonalens bemötande bidrog till att öka upplevelsen av hälsa och välbefinnande.

God hälsa på lika villkor för hela befolkningen är det övergripande målet med folkhälsoarbetet. Folkhälsoarbete innefattar planerade och systematiska insatser för att främja hälsa och förebygga sjukdom. En tydlig intention i folkhälsoarbete är att försöka påverka frisk-, skydds- och riskfaktorer samt struktur och miljöförhållanden som bidrar till en positiv hälsoutveckling. Insatserna kan vara samhälls- grupp- och individriktade. Avhandlingens fokus är på individnivå och utgår från ett salutogent synsätt där inriktningen är på hälsofrämjande faktorer. Att leva med en kronisk sjukdom som huvud- halscancer innebär att leva med en stor och tung sjukdomsörda som påverkar även närståendes vardagsliv. Då vården ofta har fokus på sjukdom och problem kan patienter uppleva maktlöshet, oro och inre stress vilket i sin tur kan öka patienternas känslor av illabefinnande. Det förefaller därför att det finnas ett ökat behov av att fokusera på vad som främjar hälsa och välbefinnande för patienter med huvud – halscancer.

Incidensen för huvud- halscancer i Norden årligen är cirka 4,500 personer och sjukdomen räknas som den femte vanligaste cancerformen. Män insjuknar två till tre gånger oftare än kvinnor. Sjukdomen är vanligast efter 50 års ålder och den blir vanligare i takt med stigande antal äldre i befolkningen. Dessutom leder en högre överlevnad till en ökad prevalens av kronisk huvud –halscancer i befolkningen.

I dagens vård ställs ett ökat krav på att hälsofrämjande insatser bör integreras i hälso- och sjukvården och att de skall vara en självklar del i behandlingen. Hälsa kan ses som en resurs och att ha hälsa kan för en person med huvud- halscancer

kan innebära upplevelsen av att må bra och fungera i vardagen, relaterat till om han/hon kan nå sina uppsatta livsmål under rimliga förhållande.

Världshälsoorganisationens (WHO) s.k. Ottawa Charters riktlinjer betonar människors egen aktivitet och förmåga att ta kontroll och makt över sin sjukdom. WHO beskriver följande grundläggande element i hälsofrämjande arbete: empowerment, jämlikhet, partnerskap, samarbete, delaktighet i samhället, självbestämmande, ömsesidigt hjälpanande och delat ansvar.

Avhandlingen omfattar fyra delarbeten baserade på kvalitativa individuella intervjuer med 35 personer med huvud- halscancer. Data insamlades vid tre tillfällen och den första studien genomfördes i Norden (delarbete **I**) med 17 deltagare från Sverige och en deltagare från var och en av de övriga fyra nordiska grannländerna. Övriga studier genomfördes i Sverige (delarbete **II**, **III**, **IV**). I delarbete **II** och **III** deltog åtta personer (samma individer) och i delarbete **IV** deltog sex andra personer. Samtliga 35 deltagare var speciellt utvalda efter följande kriterier: över 18 år med en diagnostiserad huvud- halscancer, och villiga att delge sina upplevelser av att leva med denna cancer. Deltagarna var 21 män mellan 38 och 83 år (median 60, 5 år) och 14 kvinnor mellan 59 och 81 år (median 67, 4 år). Majoriteten av deltagarna var svenskar; 26 stycken (15 män/11 kvinnor). Nio av deltagare var utlandsfödda och från sju olika länder. Då inte alla deltagarna hade svenska som modersmål genomfördes några intervjuer delvis på engelska. Detta var inte någons modersmål, men det var ett välkänt språk för både forskare och deltagare.

Flertalet av de 35 deltagarna hade talsvårigheter och ibland behövdes utökad intervjutid för upprepning av enstaka ord eller meningar. Trots dessa talsvårigheter gav personerna uttömmande och känsllosamma svar. Om deltagarna önskade att deras närstående skulle närvara för att stödja dem under intervjun godkändes detta. Övervägande antalet av deltagarna hade stora tumörer som gav problem, symtom och förändringar som var speciellt obehagliga som exempelvis att:

- 33 deltagare upplevde svårigheter att äta och svälja
- 31 deltagare hade synlig cancersvulst eller huddefekt efter operation/strålbehandling av ansikte eller nacke/hals.
- 20 deltagare hade besvärande heshet
- 18 deltagare hade ökad slembildning eller ingen saliv och extrem muntorrhet
- 16 deltagare hade artikulationssvårigheter
- 5 deltagare talade med matstrupsröst på grund av bortopererade stämband
- 4 deltagare hade extrem nasal röst

De kvalitativa individuella intervjuerna var halvstrukturerade med öppna frågor. Deltagarna intervjuades vid ett (delarbete **I, II, III**) eller flera tillfällen (delarbete **IV**) och sammanlagt gjordes 53 intervjuer. Intervjuplatsen valdes av deltagarna och genomfördes i hemmet (n= 30), på sjukhus (n=21), eller på deltagarnas arbetsplatser (n=2). Samtliga intervjuer spelades in på ljudband och varade 30-120 min. Intervjuerna skrevs ut ordagrant av intervjuaren (författaren av denna avhandling) i nära anslutning till genomförandet av intervjun för att intervjusituationen skulle ihågkommas. Utskrifterna bestod av 1083 sidor med 1,5 radavstånd.

## Resultat

- Personer med huvud - halscancer vardagsliv tolkades som ett liv i fångenskap och de upplevde sitt liv som en ständig resa i berg och dalbana; en känslomässig pendling mellan hopp och förtvivlan. De ofta livshotande symtomen upplevdes som ett hot mot existens och identitet, men de uppvisade trots detta ofta en stark optimism och framtidstro.
- Personernas inre styrka, goda relationer och känslomässiga stöd dygnet runt ifrån närstående var betydelsefullt och hjälpte dem att få kontroll och makt i vardagen.
- Aktiviteter såsom nära kontakt med natur, djur, och hobbyer skapade möjlighet för dem att hantera sitt förändrade vardagsliv och gav dem upplevelser av hälsa och välbefinnande.
- Medlemskap i patientförening var värdefullt, likaså medverka i kurser som t.ex. att lära sig leva med cancer.
- Egenvård ökade patienternas självbestämmande och minskade deras beroende av hjälp ifrån andra.
- Kvinnor med huvud- halscancer upplevde en speciell utsatthet och upplevelser av förändrade känslomässiga och sexuella relationer. Resultat visade även deltagarnas oro för sina närståendes pressade livssituationer.
- Kontakten med vården innebar för vissa personer upplevelser av maktlöshet och sårbarhet. Ett gott bemötande och goda arbetsrelationer kunde avhjälpa dessa personers upplevelser av ojämlig ställning i vården.
- Ett gott bemötande kännetecknades av en patients upplevelse av att känna samverkan och jämlikhet i en dialog med kompetent vårdpersonal. Detta hjälpte dem att få ökad egenmakt och kontroll i vardagslivet.
- Före och efter behandlingstiden var perioder där samtliga personer kände sig någon gång övergivna av vården.

- Vårdpersonalens bemötande kunde endera förstärka eller förminska personernas upplevelser av hälsa och välbefinnande.
- Bemötande och tillgängligheten var ej optimal och speciellt tydligt var detta vid personernas första kontakt med vården. Personerna upplevde ofta att de inte blev trodda eller respekterade då de beskrev sina problem. Bristen på respekt kan tyda på avsaknad av en patientcentrerad vårdorganisation med psykosocial rehabilitering.

## Kliniska implikationer för hälsofrämjande

För att främja hälsan behöver personer med huvud- halscancer tillgänglighet och kontinuitet till vårdpersonal med rätt kompetens. Därför behöver personerna stöd och samordning mellan behandlingsfaserna under sin långa sjukdomsresa utifrån en patientcentrerad vårdorganisation. Sjuksköterskemottagningar kopplade till öronklinikerna kan rekommenderas då dessa kan ha möjlighet att erbjuda psykosocial rehabilitering med trygghet och säkerhet för patienterna och deras närstående.

För att främja hälsan behöver personer med huvud- halscancer aktiviteter såsom nära kontakt med natur, djur och hobbyer. Därför behöver mer uppmärksamhet och handlingskraft läggas på skapande av hälsosam och stödjande vårdmiljö som inkluderar lättillgänglighet och planering av avskilda, tysta, avstressade rum med utsikt mot parker eller gröna ytor för både patienter och närstående. Även mer kultur i vården behövs som innefattar konst, musik och tillgång till bibliotek och kaféer.

För att främja hälsan behöver personer med huvud- halscancer fokus på inre styrka, hälsoresurser och krafter. Kanske kan därför ett salutogent synsätt i hälso- och sjukvården underlätta för patienterna att välja diskussionsämne och leda till att personerna når uppsatta livsmål, makt och kontroll över sjukdomen. Kanske krävs mer utbildning för vårdpersonal i att arbeta med ett ”botten upp” - perspektiv där patienternas aktivitet, deltagande och samarbete förstärks, detta kan speciellt tänkas förbättra resultatet vid ex. rökning och alkoholstopp.

För att främja hälsan behöver personer med huvud- halscancer mer respekt och stöd för sina värderingar och önsknings om alternativa och komplementära behandlingar tillsammans med den fastställda medicinska behandlingen. Möjligtvis behövs ytterligare utveckling och utbildning för vårdpersonal om kommunikation samt alternativa och komplementära behandlingar.

För att främja hälsan behöver personer med huvud- halscancer goda relationer och känslomässigt stöd dygnet runt för att få kontroll och makt i vardagen. Därför behöver de mest sårbara och ensamma patienterna som upplever svår känslomässig och existentiell fångenskap individualiserad vård och utökat hälsofrämjande stöd. Uppmuntran och stöd till patientorganisationer kan vara värdefullt då de kan framföra denna grups åsikter, och kanske behövs också ett utökat samarbete mellan patientorganisationer, vårdpersonal och politiker för att förbättra ekonomisk och social trygghet samt sjukvårdstrygghet för denna patientgrupp.

## Förslag på framtida forskning

- Mer salutogen forskning, speciellt för de personer med huvud- halscancer som är mest sårbara och befinner sig i beroendeställning, samt ur närståendes och vårdpersonals perspektiv.
- Genusforskning riktad mot kvinnors situation då de har huvud- halscancer.
- Arbetslivsforskning med fokus på anpassningsförmåga och hälsosam miljö, eftersom personer med huvud- halscancer har långtidspåverkan av fysiska och psykosociala men relaterade till förändrat utseende och sväljnings- och kommunikationsproblem.
- Önskvärd är ökad användning av både kvalitativ och kvantitativ forskning i praktisk verksamhet, som till exempel användande av livskvalité-instrument vid svåra behandlingsbeslut där även patientens åsikter kan värderas.

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## Appendix 1

Helsingborg 970911

Bästa.....

Mitt namn är Margereth Björklund och jag arbetar som sjuksköterska på öron avd 16 lasarettet i Helsingborg. Jag går en forskningsförberedande påbyggnadsutbildning för sjuksköterskor. Inom ramen för denna utbildning ska en undersökning utföras.

Syftet med min undersökning är att göra en kartläggning av betydelsefulla händelser som patienter beskriver för mig. Händelser som de upplevt under sin sjukdomstid då det gäller att bevara hälsa trots sjukdom. Med det menar jag frågor om händelser som gjort att Du uppnått bättre livskvalitet och fått en aktivare egenvård. Det gäller frågor om händelser vid informations- och undervisningstillfällen som att ex. äta rätt, motionera eller avhålla sig från rökning, alkohol eller droger. För att få denna kunskap behöver jag ställa dessa frågor bl.a. till Dig som patient.

Resultatet kan ge oss vårdpersonal en ökad kunskap om patienternas erfarenheter, vilket kan leda till att vi praktiskt kan förbättra vården. Undersökningen är bedömd och godkänd av forskningsetikkomittén vid Lunds Universitet.

Med detta brev vill jag informera om undersökningen och samtidigt fråga om Du kan tänkas medverka. Din medverkan är helt frivillig och Ditt ställningstagande påverkar inte Din fortsatta kontakt med sjukvården. Du har rätt att avbryta intervjun om Du ej önskar fullfölja den.

Jag har tystnadsplikt, och Din medverkan och Dina svar kommer att behandlas konfidentiellt. Vänligen fyll i svarstalongen oavsett medverkan och vilket telefonnummer jag kan få ringa upp Dig på om Du vill medverka. Var snäll att returnera talongen i bifogat kuvert inom 1 vecka. Om Du väljer att medverka kan jag komma hem till Dig eller till annan plats Du väljer för intervju. Intervjun brukar ta ca 1 timme.

Tack på förhand

Margereth Björklund

Om Du har några frågor hör gärna av Dig per telefon 042/19 18 40 (arb.)  
eller 042/22 87 68 (hem)

✂-----

Medverka

ej medverka

Namn \_\_\_\_\_ Kontakta mig per telefon \_\_\_\_\_

Förfrågan om medverkan i intervju för personer med  
Huvud och halscancer

Du tillfrågas härmed om att delta i en studie för att beskriva Dina upplevelser av hälsa och omvårdnad då Du drabbats av huvud och halscancer. Studien kan ge ökade kunskaper om hur det är att drabbas av och leva med denna cancer och också om upplevelser av och önskingar om omvårdnad. Din erfarenhet är mycket värdefull och Din medverkan kan ge viktig information som kan leda till ett förbättrat omhändertagande för denna patientgrupp i framtiden.

Intervjun beräknas ta 1 timma och kommer att spelas in på ljudband för att sedan ordagrant skrivas ut. Inga personuppgifter antecknas på bandet eller utskriften utan dessa märkes med en siffra och adresslistor upprättas separat. Bandet, utskrifterna och adresslistorna försvaras inlåst på Högskolan i Kristianstad och endast forskargruppen har tillgång till materialet. Resultatet presenteras så att Din identitet inte avslöjas. Studien bygger på frivillig medverkan, enligt bifogat formulär, och Du kan när som helst avbryta Ditt deltagande utan att ange särskilda skäl därtill och Ditt avbrott påverkar inte Din vård eller behandling. Vänligen underteckna och skicka det informerade samtycket direkt till undertecknad i det medföljande frankerade svarsbrevet. Jag återkommer sedan via telefon för att bestämma tid och plats för intervju. Du är välkommen att när som helst under studiens gång ta kontakt med undertecknad.

Med vänlig hälsning

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Margereth Björklund

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Hälsovetenskap, Högskolan Kristianstad Tfn 044-20 40 94, 042-22 87 68, mobil 070-276 33 18

E- post margereth.bjorklund@hv.hkr.se Vetenskapliga handledare: Anneli Sarvimäki, Adj. prof., Leg Sjuksköt, Fil Dr. Agneta Berg

Universitetslektor, Leg Sjuksköt Dr Med vet.



## Informerat samtycke

**Projektets titel:** Personer med huvud och halscancer beskriver sina upplevelser av hälsa och omvårdnad.

Jag är införstådd med att delta i denna studie där personer med huvud och halscancer beskriver sina upplevelser av hälsa och omvårdnad. Jag är införstådd med att mina svar kommer att vara underlag för studien.

Jag är införstådd med att intervjuerna spelas in på ljudband och skrivs ut.

Jag är införstådd med att mitt deltagande är frivilligt och att jag kan avbryta mitt deltagande när som helst utan förklaring, utan att det påverkar vidare omhändertagande i vården.

Jag är införstådd med att jag kan ställa frågor om studien när som helst, nu eller i framtiden.

Jag är införstådd med att mina svar förblir konfidentiella och att presentationen av resultatet inte avslöjar min identitet.

Härmed samtycker jag till att delta i denna studie.

\_\_\_\_\_  
Ort

datum

\_\_\_\_\_  
Namnunderskrift

\_\_\_\_\_  
Namnförtydligande

Tfn. Bostad \_\_\_\_\_ Tfn Arbete \_\_\_\_\_ Mobil Tfn. \_\_\_\_\_

E-post \_\_\_\_\_

Vänligen underteckna och skicka detta svar direkt till forskaren i det frankerade svarsbrev.

Därefter kontaktar forskaren Dig via telefon. Intervjupersonen får en kopia av denna signerade och daterade samtyckes informationen vid intervjun. Originalet förvaras konfidentiellt. <sup>1</sup>

\_\_\_\_\_  
<sup>1</sup>För vidare information kontakta

# Förteckning över NHV-rapporter

## 1983

- 1983:1 Hälsa för alla i Norden år 2000. Föredrag presenterade på en konferens vid Nordiska hälsovårdshögskolan 7–10 september 1982.
- 1983:2 Methods and Experience in Planning for Family Health – Report from a seminar. Harald Heijbel & Lennart Köhler (eds).
- 1983:3 Accident Prevention – Report from a seminar. Ragnar Berfenstam & Lennart Köhler (eds).
- 1983:4 Själv mord i Stockholm – en epidemiologisk studie av 686 konsekutiva fall. Thomas Hjortsjö. Avhandling.

## 1984

- 1984:1 Långvarigt sjuka barn – sjukvårdens effekter på barn och familj. Andersson, Harwe, Hellberg & Syrén. (FoU-rapport/shstf:14). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.
- 1984:2 Intersectoral Action for Health – Report from an International Workshop. Lennart Köhler & John Martin (eds).
- 1984:3 Barns hälsotillstånd i Norden. Gunborg Jakobsson & Lennart Köhler. Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.

## 1985

- 1985:1 Hälsa för äldre i Norden år 2000. Märten Lagergren (red).
- 1985:2 Socialt stöd åt handikappade barn i Norden. Mats Eriksson & Lennart Köhler. Distribueras av Allmänna Barnhuset, Box 26006, SE-100 41 Stockholm.
- 1985:3 Promotion of Mental Health. Per-Olof Brogren.
- 1985:4 Training Health Workers for Primary Health Care. John Martin (ed).
- 1985:5 Inequalities in Health and Health Care. Lennart Köhler & John Martin (eds).

## 1986

- 1986:1 Prevention i primärvården. Rapport från konferens. Harald Siem & Hans Wedel (red). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.
- 1986:2 Management of Primary Health Care. John Martin (ed).
- 1986:3 Health Implications of Family Breakdown. Lennart Köhler, Bengt Lindström, Keith Barnard & Houda Itani.
- 1986:4 Epidemiologi i tandvården. Dorthe Holst & Jostein Rise (red). Distribueras av Tandläkarförlaget, Box 5843, SE-102 48 Stockholm.
- 1986:5 Training Course in Social Pediatrics. Part I. Lennart Köhler & Nick Spencer (eds).

# Förteckning över NHV-rapporter

## 1987

- 1987:1 Children's Health and Well-being in the Nordic Countries. Lennart Köhler & Gunborg Jakobsson. Ingår i serien Clinics in Developmental Medicine, No 98 och distribueras av Blackwell Scientific Publications Ltd, Oxford. ISBN (UK) 0 632 01797X.
- 1987:2 Traffic and Children's Health. Lennart Köhler & Hugh Jackson (eds).
- 1987:3 Methods and Experience in Planning for Health. Essential Drugs. Frants Staugård (ed).
- 1987:4 Traditional midwives. Sandra Anderson & Frants Staugård.
- 1987:5 Nordiska hälsovårdshögskolan. En historik inför invigningen av lokalerna på Nya Varvet i Göteborg den 29 augusti 1987. Lennart Köhler (red).
- 1987:6 Equity and Intersectoral Action for Health. Keith Barnard, Anna Ritsatakis & Per-Gunnar Svensson.
- 1987:7 In the Right Direction. Health Promotion Learning Programmes. Keith Barnard (ed).

## 1988

- 1988:1 Infant Mortality – the Swedish Experience. Lennart Köhler.
- 1988:2 Familjen i välfärdsstaten. En undersökning av levnadsförhållanden och deras fördelning bland barnfamiljer i Finland och övriga nordiska länder. Gunborg Jakobsson. Avhandling.
- 1988:3 Aids i Norden. Birgit Westphal Christensen, Allan Krasnik, Jakob Bjørner & Bo Eriksson.
- 1988:4 Methods and Experience in Planning for Health – the Role of Health Systems Research. Frants Staugård (ed).
- 1988:5 Training Course in Social Pediatrics. Part II. Perinatal and neonatal period. Bengt Lindström & Nick Spencer (eds).
- 1988:6 Äldretandvård. Jostein Rise & Dorthe Holst (red). Distribueras av Tandläkarförlaget, Box 5843, SE-102 48 Stockholm.

## 1989

- 1989:1 Rights, Roles and Responsibilities. A view on Youth and Health from the Nordic countries. Keith Barnard.
- 1989:2 Folkhälsovetenskap. Ett nordiskt perspektiv. Lennart Köhler (red).
- 1989:3 Training Course in Social Pediatrics. Part III. Pre-School Period. Bengt Lindström & Nick Spencer (eds).

## Förteckning över NHV-rapporter

- 1989:4 Traditional Medicine in Botswana. Traditional Medicinal Plants. Inga Hedberg & Frants Staugård.
- 1989:5 Forsknings- och utvecklingsverksamhet vid Nordiska hälsovårdshögskolan. Rapport till Nordiska Socialpolitiska kommittén.
- 1989:6 Omstridda mödrar. En studie av mödrar som förtecknats som förståndshandikappade. Evy Kollberg. Avhandling.
- 1989:7 Traditional Medicine in a transitional society. Botswana moving towards the year 2000. Frants Staugård.
- 1989:8 Rapport fra Den 2. Nordiske Konferanse om Helseopplysning. Bergen 4–7 juni 1989. Svein Hindal, Kjell Haug, Leif Edvard Aarø & Carl-Gunnar Eriksson.

### 1990

- 1990:1 Barn och barnfamiljer i Norden. En studie av välfärd, hälsa och livskvalitet. Lennart Köhler (red). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.
- 1990:2 Barn och barnfamiljer i Norden. Teknisk del. Lennart Köhler (red).
- 1990:3 Methods and Experience in Planning for Health. The Role of Women in Health Development. Frants Staugård (ed).
- 1990:4 Coffee and Coronary Heart Disease, Special Emphasis on the Coffee – Blood Lipids Relationship. Dag S. Thelle & Gerrit van der Stegen (eds).

### 1991

- 1991:1 Barns hälsa i Sverige. Kunskapsunderlag till 1991 års Folkhälsorapport. Gunborg Jakobsson & Lennart Köhler. Distribueras av Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna Förlaget).
- 1991:2 Health Policy Assessment – Proceedings of an International Workshop in Göteborg, Sweden, February 26 – March 1, 1990. Carl-Gunnar Eriksson (ed). Distributed by Almqvist & Wiksell International, Box 638, SE-101 28 Stockholm.
- 1991:3 Children's health in Sweden. Lennart Köhler & Gunborg Jakobsson. Distributed by Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna Förlaget).
- 1991:4 Poliklinikker og dagkurgi. Virksomhetsbeskrivelse for ambulent helsetjeneste. Monrad Aas.
- 1991:5 Growth and Social Conditions. Height and weight of Stockholm schoolchildren in a public health context. Lars Cernerud. Avhandling.
- 1991:6 Aids in a caring society – practice and policy. Birgit Westphal Victor. Avhandling
- 1991:7 Resultat, kvalitet, valfrihet. Nordisk hälsopolitik på 90-talet. Mats Brommels (red). Distribueras av nomesko, Sejrøgade 11, DK-2100 København.

# Förteckning över NHV-rapporter

## 1992

- 1992:1      Forskning om psykiatrisk vårdorganisation – ett nordiskt komparativt perspektiv. Mats Brommels, Lars-Olof Ljungberg & Claes-Göran Westin (red). sou 1992:4. Distribueras av Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna förlaget).
- 1992:2      Hepatitis virus and human immunodeficiency virus infection in dental care: occupational risk versus patient care. Flemming Scheutz. Avhandling.
- 1992:3      Att leda vård – utveckling i nordiskt perspektiv. Inga-Maja Rydholm. Distribueras av shstf-material, Box 49023, SE-100 28 Stockholm.
- 1992:4      Aktion mot alkohol och narkotika 1989–1991. Utvärderingsrapport. Athena. Ulla Marklund.
- 1992:5      Abortion from cultural, social and individual aspects. A comparative study, Italy – Sweden. Marianne Bengtsson Agostino. Avhandling.

## 1993

- 1993:1      Kronisk syke og funksjonshemmede barn. Mot en bedre fremtid? Arvid Heiberg (red). Distribueras av Tano Forlag, Stortorget 10, NO-0155 Oslo.
- 1993:2      3 Nordiske Konference om Sundhedsfremme i Aalborg 13 – 16 september 1992. Carl-Gunnar Eriksson (red).
- 1993:3      Reumatikernas situation i Norden. Kartläggning och rapport från en konferens på Nordiska hälsovårdshögskolan 9 – 10 november 1992. Bjarne Jansson & Dag S. Thelle (red).
- 1993:4      Peace, Health and Development. A Nobel seminar held in Göteborg, Sweden, December 5, 1991. Jointly organized by the Nordic School of Public Health and the University of Göteborg with financial support from SAREC. Lennart Köhler & Lars-Åke Hansson (eds).
- 1993:5      Hälsopolitiska jämlikhetsmål. Diskussionsunderlag utarbetat av WHO's regionkontor för Europa i Köpenhamn. Göran Dahlgren & Margret Whitehead. Distribueras gratis.

## 1994

- 1994:1      Innovation in Primary Health Care of Elderly People in Denmark. – Two Action Research Projects. Lis Wagner. Avhandling.
- 1994:2      Psychological stress and coping in hospitalized chronically ill elderly. Mary Kalfoss. Avhandling.
- 1994:3      The Essence of Existence. On the Quality of Life of Children in the Nordic countries. Theory and Practice. Bengt Lindström. Avhandling.

# Förteckning över NHV-rapporter

## 1995

- 1995:1 Psykiatrisk sykepleie i et folkehelseperspektiv. En studie av hvordan en holistisk-eksistensiell psykiatrisk sykepleiemodell bidrar til folkehelsearbeid. Jan Kåre Hummelvoll. Avhandling.
- 1995:2 Child Health in a Swedish City – Mortality and birth weight as indicators of health and social inequality. Håkan Elmén. Avhandling.
- 1995:3 Forebyggende arbeid for eldre – om screening, funn, kostnader og opplevd verdi. Grethe Johansen. Avhandling.
- 1995:4 Clinical Nursing Supervision in Health Care. Elisabeth Severinsson. Avhandling.
- 1995:5 Prioriteringsarbeid inom hälso- och sjukvården i Sverige och i andra länder. Stefan Holmström & Johan Calltorp. Sprit 1995. Distribueras av Spris förlag, Box 70487, SE-107 26 Stockholm.

## 1996

- 1996:1 Socialt stöd, livskontroll och hälsa. Raili Peltonen. Socialpolitiska institutionen, Åbo Akademi, Åbo, 1996.
- 1996:2 Recurrent Pains – A Public Health Concern in School – Age Children. An Investigation of Headache, Stomach Pain and Back Pain. Gudrún Kristjánsdóttir. Avhandling.
- 1996:3 AIDS and the Grassroots. Frants Staugård, David Pitt & Claudia Cabrera (red).
- 1996:4 Postgraduate public health training in the Nordic countries. Proceedings of seminar held at The Nordic School of Public Health, Göteborg, January 11 – 12, 1996.

## 1997

- 1997:1 Victims of Crime in a Public Health Perspective – some typologies and tentative explanatory models (Brottsoffer i ett folkhälsoperspektiv – några typologier och förklaringsmodeller). Barbro Renck. Avhandling. (Utges både på engelska och svenska.)
- 1997:2 Kön och ohälsa. Rapport från seminarium på Nordiska hälsovårdshögskolan den 30 januari 1997. Gunilla Krantz (red).
- 1997:3 Edgar Borgenhammar – 65 år. Bengt Rosengren & Hans Wedel (red).

## 1998

- 1998:1 Protection and Promotion of Children's Health – experiences from the East and the West. Yimin Wang & Lennart Köhler (eds).
- 1998:2 EU and Public Health. Future effects on policy, teaching and research. Lennart Köhler & Keith Barnard (eds) 1998:3 Gender and Tuberculosis. Vinod K. Diwan, Anna Thorson, Anna Winkvist (eds)

# Förteckning över NHV-rapporter

Report from the workshop at the Nordic School of Public Health, May 24-26, 1998.

## 1999

- 1999:1 Tipping the Balance Towards Primary Healthcare Network. Proceedings of the 10th Anniversary Conference, 13-16 November 1997. Editor: Chris Buttanshaw.
- 1999:2 Health and Human Rights. Report from the European Conference held in Strasbourg 15-16 mars 1999. Editor: Dr. med. Stefan Winter.
- 1999:3 Learning about health: The pupils' and the school health nurses' assessment of the health dialogue. Ina Borup. DrPH-avhandling.
- 1999:4 The value of screening as an approach to cervical cancer control. A study based on the Icelandic and Nordic experience through 1995. Kristjan Sigurdsson. DrPH-avhandling.

## 2000

- 2000:1 Konsekvenser av urininkontinens sett i et folkehelsevitenskapelig perspektiv. En studie om livskvalitet hos kvinner og helsepersonells holdninger. Anne G Vinsnes. DrPH-avhandling.
- 2000:2 A new public health in an old country. An EU-China conference in Wuhan, China, October 25-29, 1998. Proceedings from the conference. Lennart Köhler (ed)
- 2000:3 Med gemenskap som grund - psykisk hälsa och ohälsa hos äldre människor och psykiatrisjuksköterskans hälsofrämjande arbete. Birgitta Hedelin. DrPH-avhandling.
- 2000:4 ASPHER Peer Review 1999. Review Team: Jacques Bury, ASPHER, Franco Cavallo, Torino and Charles Normand, London.
- 2000:5 Det kan bli bättre. Rapport från en konferens om barns hälsa och välfärd i Norden. 11-12 november 1999. Lennart Köhler. (red)
- 2000:6 Det är bra men kan bli bättre. En studie av barns hälsa och välfärd i de fem nordiska länderna, från 1984 till 1996. Lennart Köhler, (red)
- 2000:7 Den svenska hälso- och sjukvårdens styrning och ledning – en delikat balansakt. Lilian Axelsson. DrPH-avhandling.
- 2000:8 Health and well-being of children in the five Nordic countries in 1984 and 1996. Leeni Berntsson. DrPH-avhandling.
- 2000:9 Health Impact Assessment: from theory to practice. Report on the Leo Kaprio Workshop, Göteborg, 28 - 30 October 1999.

## 2001

- 2001:1 The Changing Public-Private Mix in Nordic Healthcare - An Analysis  
John Øvretveit.

## Förteckning över NHV-rapporter

- 2001:2 Hälsokonsekvensbedömningar – från teori till praktik. Rapport från ett internationellt arbetsmöte på Nordiska hälsovårdshögskolan den 28-31 oktober 1999. Björn Olsson, (red)
- 2001:3 Children with asthma and their families. Coping, adjustment and quality of life. Kjell Reichenberg. DrPH-avhandling.
- 2001:4 Studier av bruket av dextropropoxifen ur ett folkhälsoperspektiv. Påverkan av ett regelverk. Ulf Jonasson. DrPH-avhandling.
- 2001:5 Protection – Prevention – Promotion. The development and future of Child Health Services. Proceedings from a conference. Lennart Köhler, Gunnar Norvenius, Jan Johansson, Göran Wennergren (eds).
- 2001:6 Ett pionjärbete för ensamvargar  
Enkät- och intervjuundersökning av nordiska folkhälsodoktorer examinerade vid Nordiska hälsovårdshögskolan under åren 1987 – 2000.  
Lillemor Hallberg (red).

### 2002

- 2002:1 Attitudes to prioritisation in health services. The views of citizens, patients, health care politicians, personnel, and administrators. Per Rosén. DrPH-avhandling.
- 2002:2 Getting to cooperation: Conflict and conflict management in a Norwegian hospital. Morten Skjørshammer. DrPH-avhandling.
- 2002:3 Annual Research Report 2001. Lillemor Hallberg (ed).
- 2002:4 Health sector reforms: What about Hospitals? Pär Eriksson, Ingvar Karlberg, Vinod Diwan (ed).

### 2003

- 2003:1 Kvalitetsmåling i Sundhedsvæsenet.  
Rapport fra Nordisk Ministerråds Arbejdsgruppe.
- 2003:3 NHV 50 år (Festboken)
- 2003:4 Pain, Coping and Well-Being in Children with Chronic Arthritis.  
Christina Sällfors. DrPH-avhandling.
- 2003:5 A Grounded Theory of Dental Treatments and Oral Health Related Quality of Life.  
Ulrika Trulsson. DrPH-avhandling.

### 2004

- 2004:1 Brimhealth: Baltic rim partnership for public health 1993-2003.  
Susanna Bihari-Axelsson, Ina Borup, Eva Wimmerstedt (eds)
- 2004:2 Experienced quality of the intimate relationship in first-time parents – qualitative and quantitative studies. Tone Ahlborg. DrPH-avhandling.

# Förteckning över NHV-rapporter

## 2005

- 2005:1 Kärlek och Hälsa – Par-behandling i ett folkhälsoperspektiv.  
Ann-Marie Lundblad. DrPH-avhandling.
- 2005:2 1990 - 2000:A Decade of Health Sector Reform in Developing Countries  
- Why, and What Did we Learn?  
Erik Blas. DrPH-avhandling
- 2005:3 Socio-economic Status and Health in Women  
Population-based studies with emphasis on lifestyle and cardiovascular disease  
Claudia Cabrera. DrPH-avhandling

## 2006

- 2006:1 "Säker Vård -patientskador, rapportering och prevention"  
Synnöve Ödegård. DrPH-avhandling
- 2006:2 Interprofessional Collaboration in Residential Childcare  
Elisabeth Willumsen. DrPH-avhandling
- 2006:3 Inkomst-CTG: En vurdering av testens prediktive verdier, reliabilitet og  
effekt. Betydning for jordmødre i deres daglige arbeide  
Ellen Blix. DrPH-avhandling

## 2007

- 2007:1 Health reforms in Estonia - acceptability, satisfaction and impact  
Kaja Põlluste. DrPH-avhandling
- 2007:2 Creating Integrated Health Care  
Bengt Åhgren. DrPH-avhandling
- 2007:3 Alkoholbruk i tilknytning til arbeid – Ein kvalitativ studie i eit folkehelsevitskapeleg  
perspektiv  
Hildegunn Sagvaag. DrPH-avhandling
- 2007:4 Public Health Aspects of Pharmaceutical Prescription Patterns – Exemplified by  
Treatments for Prevention of Cardiovascular Disease  
Louise Silwer. DrPH-avhandling
- 2007:5 Å fremme den eldre sykehuspasientens helse I lys av et folkehelse og holistisk-  
eksistensielt sykepleieperspektiv  
Geir V Berg. DrPH-avhandling

## 2008

- 2008:1 Diabetes in children and adolescents from non-western immigrant families –  
health education, support and collaboration  
Lene Povlsen. DrPH-avhandling

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- 2008:2 Love that turns into terror: Intimate partner violence in Åland – nurses' encounters with battered women in the context of a government-initiated policy programme  
Anette Häggblom. DrPH-avhandling
- 2008:3 Oral hälsa hos personer med kognitiva och/eller fysiska funktionsnedsättningar – ett dolt folkhälsoproblem? Ulrika Hallberg, Gunilla Klingberg
- 2008:4 School health nursing – Perceiving, recording and improving schoolchildren's health  
Eva K Clausson. DrPH-avhandling
- 2008:5 Helbredsrelateret livskvalitet efter apopleksi. Validering og anvendelse af SSQOL-DK, et diagnosespecifikt instrument til måling af helbredsrelateret livskvalitet blandt danske apopleksipatienter  
Ingrid Muus. DrPH-avhandling
- 2008:6 Social integration for people with mental health problems: experiences, perspectives and practical changes  
Arild Granerud. DrPH-avhandling
- 2008:7 Between death as escape and the dream of life. Psychosocial dimensions of health in young men living with substance abuse and suicidal behaviour  
Stian Biong. DrPH-avhandling
- 2009**
- 2009:1 Ut ur ensamheten. Hälsa och liv för kvinnor som varit utsatta för sexuella övergrepp i barndomen och som deltagit i självhjälpsgrupp  
GullBritt Rahm. DrPH-avhandling
- 2009:2 Development of Interorganisational Integration – A Vocational Rehabilitation Project  
Ulla Wihlman. DrPH-avhandling
- 2009:3 Hälsa- och sjukvårdens roll som informationskälla för hälsoläget i befolkningen och uppföljning av dess folkhälsoinriktade insatser  
Sirkka Elo. DrPH-avhandling
- 2009:4 Folkesundhed i børnehøjde - indikatorer for børns sundhed og velbefindende i Grønland  
Birgit Niclasen. DrPH-avhandling
- 2009:5 Folkhälsoforskning i fem nordiska länder - kartläggning och analys  
Stefan Thorpenberg
- 2009:6 Ledarskap och medarbetarskap vid strukturella förändringar i hälso- och sjukvården. Nyckelaktörers och medarbetares upplevelser  
Agneta Kullén Engström. DrPH-avhandling
- 2009:7 Perspective of risk in childbirth, women's expressed wishes for mode of delivery and how they actually give birth  
Tone Kringeland. DrPH-avhandling

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An 18 year follow-up study from the perspective of young adults  
Ingrid Landgraff Østlie. DrPH-avhandling
- 2009:9 Åldrande, hälsa, minoritet - äldre finlandssvenskar i Finland och Sverige  
Gunilla Kulla. DrPH-avhandling
- 2010**
- 2010:1 Att värdera vårdbehov - ett kliniskt dilemma. En studie av nyttjandet av  
ambulanssjukvård i olika geografiska områden  
Lena Marie Beillon. DrPH-avhandling
- 2010:2 R Utvärdering av samverkansprojekt med remissgrupper och samverkansteam i  
Norra Dalsland
- 2010:3 R Utvärdering av verksamheten vid Enheten för Asyl- och flyktingfrågor,  
Västra Götalandsregionen
- 2010:4 R Utvärdering av försöksverksamhet med samverkansgrupper och coacher i  
Vänersborg och Mellerud
- 2010:5 R Utvärdering av projekt GEVALIS – Unga vuxna
- 2010:6 R Utvärdering av Program Sexuell hälsa, Västra Götalandsregionen
- 2010:7 Perceptions of public health nursing practice - On borders and boundaries,  
visibility and voice  
Anne Clancy. DrPH-avhandling
- 2010:8 Living with head and neck cancer: a health promotion perspective – A  
Qualitative Study  
Margereth Björklund. DrPH-avhandling

Head and neck cancer (HNC) is a life-threatening and chronic illness. The findings revealed that the patients' inner strength and good relationships with next of kin and contact with nature, hobbies, and activities could create a sense of empowerment and experiences of better health and well-being. Consequently, it is important to design pleasing health-care environments that include green spaces and views to parks and encompass cultural activities such as art, music, and access to libraries and cafés.

Health professionals' views of mankind, roles, and behaviours could either strengthen or weaken the patients' health and well-being. Both *health promoting* and *not health promoting* contacts and care were experienced.

Not every patient was strong enough to find health and well-being, some patients felt vulnerable, isolated, and had feelings of being alone. They were aware of the strained situation experienced by their next of kin in providing needed emotional and practical support 24 hours a day. Health and social services that better meet the needs of HNC patients ought to be developed through the co-operation of patient organisations, health professionals, and policy makers. The findings highlight the need for a salutogen perspective and attentiveness in caring for HNC patients, especially for those who feel vulnerable, dependent, and have lower self-esteem and autonomy.

