

A Health Promotion Perspective of Living with Head and Neck Cancer

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1. Introduction

1.1 Public health and head and neck cancer

All definitions of public health share a mutual aim, i.e. to decrease disease and preserve health (Beaglehole & Bonita, 2001). In the nineteenth century public health (i.e. the old public health approach), search for changes in the physical environment and point at e.g. education of personal hygiene, and development of social standard of living satisfactory for maintenance of health, further infection control, medical and nursing services for early diagnosis and preventive treatment of disease. In the mid-1970s, the movement towards a new public health approach sought changes in, social, political, economic and environmental conditions believed to enhance health. The topics are fundamental, 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 to income, educational status, and not least to social relationship to others. All these factors seem to prompt linking public health research to individuals and groups living with Head and Neck Cancer [HNC]. Additional, it is not uncommon that the location of the tumour and the side effects of treatment (surgery and radiation) often result in everlasting, 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 worries, considering the face is the initial focus in encounters and central to verbal and non-verbal communication (Rumsey et al., 2004). Even a brief glimpse of the affected person informs the observer of a dissimilarity of ordinary look. Furthermore, these persons often have poor speech and might avoid social contact, often restricting them to a close circle of friends and relatives (ibid).

When a person contracts an HNC disease he/she always carries the primary concern for individual health. If he/she is too sick, the responsibility shifts to the next of kin. As a final point, the responsibility shifts to society. On the individual level, public health aims to promote health and enhance comfort to those groups and individuals that are most vulnerable to ill health (Beaglehole & Bonita, 2001). Patients with HNC search for relief and health resources when they experience lifelong feelings of ill health (cf. Aarstad, 2008). Nevertheless, it seems to be challenging for them to achieve better health and well-being since they live constantly with chronic problems, e.g. swallowing and eating disorders that go with their increasing age.

1.2 Head and neck cancer

HNC is comprised mainly of squamous cell and adenocarcinoma and includes cancer of the lip, mouth, sinuses, ear, nose, salivary gland, thyroid, larynx, tongue, pharynx and oropharynx, nasopharynx, and hypopharynx (cf. Feber, 2000). HNC is most common in people in aged >50 years, and the percentage of aged patients is rising due to the increasing lifespan. HNC presents diverse aetiologies and pathology, but tobacco and alcohol use, particularly in combination, are known risk factors (cf. Langius, 1995). The pattern of HNC is not same for both sexes, e.g. women have three to four time greater chance for thyroid cancer than men have (cf. Feber, 2000). In contrast, cancer incidence in the tonsils has increased threefold in men since 1970s and this could be an indication of an epidemic of virus-induced carcinoma, since nearly all tonsils cancer originates from a human papilloma virus infection of the mucosa (Näsman et al., 2009). HNC is the fifth most common cancer in the Nordic countries and the annual incidence of this cancer is increasing, and its prevalence reflects a long term survival rate. The survival rate has increased in recent decades due to the many advances in surgery and development in combining radiation therapy and chemotherapy. These findings correspond to other cancer research showing that advancements in cancer research have reduced the risk of cancer death across lifespan. Consequently, cancer should be recognised as a chronic illness (cf. Carnevali & Reiner, 1990).

Traditionally, Western medicine that follows oncology guidelines is used in treating HNC in Denmark, Finland, Island, Norway and Sweden. 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. Additional factors are patients' wishes, cooperation, physical function, social status, and education, experience, and physician qualifications (cf. Feber, 2000).

Radiotherapy is standardised with 60 to 68 Grey given once or twice a day, five days a week, for 35 to 50 days. Unceasing improvement in radiotherapy are allowing clinicians to target only the diseased tissues, thus resulting of fewer side effects compared to previous therapy (Sharp, 2006). Likewise, chemotherapy has also advanced and can be used as both curative and palliative treatment, or as an integral part of radiotherapy, with drugs given five days on three or more occasions (cf. Aarstad, 2008).

These treatment offer cure and/or palliation for patients but have also side effects such as acute breathing and bleeding problems. In addition to long-term changes with swallowing and/or communication, this could cause psychological and existential problems for patients (cf. Björklund, 2010). In recent decades, services for patients' emotional and practical needs related to support, care, and knowledge have been available at ear, nose, and throat clinic (cf. Larsson, 2006). However these clinics are not easily accessible for everyone with HNC, since the patients often need acute support when experiencing harsh side effects of treatment. Access to health care can be difficult and frequently patients try to find additional treatment known to be health promoting in people with cancer (cf. Hök, 2009). This treatment is often referred as complementary and alternative medicine, but this and traditional medicine is context-dependent (World Health Organisation [WHO], 2002). The term complementary and alternative medicine speaks of a set of health care practices that are not part of a country's own traditions, or not integrated into a dominant health care

system. Hence, a particular practice such as acupuncture might be referred as complementary and alternative medicine or treatment in Western (developed) countries, while it is classified as traditional medicine in China. Traditional medicine includes diverse health practices, approaches, knowledge, and beliefs to treat, diagnose, or prevent illness. 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 and human touch are shown to be effective and valuable for patients' with different cancer forms (Leddy, 2003). 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. 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 (cf. Dossey et al., 2000).

1.3 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 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). But the patient's symptoms progress to become a struggle of daily problems with breathing, bleeding, odour from nose or mouth, eating, swallowing, fatigue, speaking, and pain in addition to changes in appearance. Larsson (2006) revealed the patients' eating and swallowing problems as a very specific contextual phenomenon, and highlight the need to focus on the patients' needs on the whole. Patients' nutritional problems often lead to extreme weight loss, in addition to fatigue. Fatigue is a subjective, unpleasant symptom, especially during and after radiotherapy and can range from tiredness to exhaustion. Together with pain in the shoulder and arm, due to neck dissection, it affects with the patient's ability to perform domestic tasks (cf. Björklund, 2010). Also, patients' complex communication problems, with limited speech or no voice at all, complicates life and their contact with health professionals. Also, patients must often learn to live, and 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 (Björklund, 2010). 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 the patients can experience better health (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 (cf. Björklund, 2010). These thoughts and behaviour of maintaining well-being can be understood through the Shifting Perspectives Model of Chronic Illness (Thorne & Paterson, 1998; Paterson, 2001). This model suggested that people with chronic illness has element of both illness and wellness that effect 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 putting 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 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 prevent individuals from getting the service or attention they need since patients are forced to focus on their limitations and weakness to receive 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. The model illustrate that the perspective is not static and suggest 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).

1.4 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*, 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 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 patient's personal strength and health resources, i.e. salutogenic factors, and supposedly contributes directly to health and predicts favourable health outcomes. 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 the 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 their 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 (Björklund et al., 2010). 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. 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 potentials, i.e. their own health resources. If the person feels well and can function in his/her social context, then that is their experience of health and feelings of well-being irrespective of illness or health condition (Nordenfelt, 1995).

1.5 Health promotion

The concept of health promotion is a theoretical concept and has been interpreted in many ways. Expressions such as equality, partnership, collaboration, participation, self-determination and 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, not a responsibility for health services alone, since subjective feeling of health and well-being are a necessity and require participation from the individual self.

Leddy (2003) highlight to look at the patients as active individuals with strength to decide for themselves what they think promotes their health. 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 actions. 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 (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 individuals' 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 (*cf.* Feber, 2000). Yet, giving up these habits will not directly lead to achieving vital goals in life; nor will it spontaneously reinforce patient's ability to act (Aarstad, 2008). Further, Allison's (2002) research shows that using wine during recovery can lead to decreased sense of illness. It is also known that intake of citrus fruits could be protective and reduce risk of developing a secondary primary tumour in the lung, but often the patients' anatomical problems make it impossible to eat the recommended food (Larsson, 2006). Pender (1996) stresses that 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) perceived 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. 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 (Young & Hayes, 2002). Effective communication, understanding and insight were experienced as enhancing health and well-being for patients in HNC care (Richardson, 2002). 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 attributed 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 positive human encounter when receiving care, patients need respect and balance in every care contact with health professionals (National Institute of Public Health [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 individuals' 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. Empowerment is part in 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 (Dossey et al., 2000), in particular when defined as the ability to act to realise vital goals (Nordenfelt, 1995). It may be understood to promote health if it implies the growing capability of patients to succeed in their self-formulate goals, with an outcome of better health. 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, creating of autonomous decision making and ultimately a mastery over and acceptance over the illness and the meaning in everyday life.

1.6 Rationale of the studies

The intent of the studies is to describe 35 participants' experiences from a health promotion and salutogenic perspective. There is a value in focusing on patients' personal strength 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 problems 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. HNC often causes visible disfigurement combined with speech and eating disorders that could lead to psychosocial problems. Such features 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 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.

2. Aims

The studies 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.

2.1 Specific aims

- to describe cancer patients' experiences of nurses' behaviour in terms of critical incidents after nurses had given them health promotion care (Björklund & Fridlund, 1999; paper I).
- to describe the characteristics of health promoting contacts with health professionals as encountered by individuals with head and neck cancer (Björklund et al., 2009; paper II).
- to shed light on health promotion from the perspective of individuals living with head and neck cancer (Björklund et al., 2008; paper III).
- to illuminate what it means to live with head and neck cancer (Björklund et al., 2010; paper IV).

3. Methods

3.1 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 (Polit & Beck, 2008). The design is flexible, and the researcher is the tool for data collection and analysis while engaging in on-going reflection and decision-making throughout the studies' progression. The studies 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. Furthermore, it was not the intention to conduct comparative research between the countries.

3.2 Study context

The first study was conducted from 1997 through 1998 in the Nordic countries (paper I), and the second study during 2005 in Sweden (paper II and 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 inpatients care in general to short hospital visits and outpatient care. Adding, policymakers have stipulate sharper guiding principles towards more health promoting care (cf. NIPH, 2005).

3.3 Participants

All patients' (n= 35) interviewed were purposively selected in consultation with medical and nursing staff involved in their care. The selection criteria were:

- Men and women above age of 18 years
- 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 (six men and three women) originated from seven other 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 grand-children. 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; median 48.6 years) and seven were women (aged 32-80; 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** and **III**). All agreed to participate in the last study (paper **IV**). In nearly half of the participants (n= 15), seven men and eight 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. The severity of the HNC sickness 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

3.4 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

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) ¹⁾
Nasal cancer	1	1/0
Oro-pharyngeal cancer	1	0/1
Unspecified head and neck cancer	2	1/1
Oesophagus cancer	0	0/0 (0/1) ¹⁾
Salivary gland cancer	1	0/1
Tongue cancer	4	2/2
Tonsil cancer	7	6/1
Thyroidal cancer	1	0/1
<i>Other solitary cancer in the body</i>	5	2/3 ²⁾

Table 1. Presents an overview of the 35 participants' diagnosis and was designed to include the specific diagnoses while ensuring the confidentiality and integrity of all participants when grouped together. ¹⁾ Side diagnoses are indicated in brackets, ²⁾ Prostate, stomach, breast, lymphoma, and melanoma.

guide was constructed by following Flanagan's (1954) advices, i.e. questions were derived from the aim of the study (Björklund & Fridlund, 1999). 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-constructed 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 topic for paper II (Björklund et al., 2009) and one for paper III (Björklund et al., 2008). After revision, all participants were re-interviewed using the two-part guide. The first three test interviews were included into the respectively participant's interview. A semi-structured guide was further 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 (Björklund et al., 2010).

3.5 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 (Björklund & Fridlund, 1999, Björklund et al., 2008, 2009) while others were interviewed up to four times (Björklund et al., 2010). 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 performed in English. Neither the participant nor the interviewer had English as their native language, but all were familiar with the language. Body language was also used frequently, e.g. facial expressions and lip movement or pointing at the body to describe surgery, pain, disgust or cheerfulness. Some participants clarified their answers in writing or 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. All discussions during the interviews were tape recorded. The interviews lasted 30-120 minutes, but contact time with the patients was substantially longer. The researcher 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).

3.6 Text analyses

Owing to the richness of the text and the ability to interpret the data on different levels, different qualitative analyses were used for 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 (Polit & Beck, 2008). 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 'read thread' throughout the condensed meanings units, codes or sub-categories A meaning unit is a constellation of statements or words that relate to the same meaning, and codes are a process of identifying recurring words, themes, or concepts within these meanings units. There are different levels or dimensions of interpretations ranging from the concrete surface level of words down to 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, thus, the text analysis was open to several possible interpretations. The first study (Bjorklund & Fridlund, 1999) was analysed with the critical incident technique (Flanagan, 1954). The second study (Bjorklund et al., 2008; 2009) with a qualitative content analysis i.e. thematic and latent (Berg, 2004). The last study (Bjorklund et al., 2010) was analysed with an interpretative descriptive analysis (Thorne et al., 1997; Thorne et al., 2004).

3.6.1 Critical incident technique

In 1954, Flanagan described the critical incident technique and this method obtains data from participants by in-depth exploration of critical incidents and human behaviours related to the topic under study. The technique differs from 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, acting or behaviour, and the result. This study (Bjorklund & Fridlund, 1999) 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 positive or negative impact on the patients' experience of feeling better health and well-being. All the 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. Then the categories were placed into one of the main areas (ibid).

3.6.2 Qualitative content analysis

The 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 (Baxter, 1991) and latent (Berg, 2004) qualitative content offers alternatives for analysis when researcher use wording to develop qualitative descriptions when analysing different qualitative content of text. The questions to the 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 holds participants' wishes for health promoting contacts, since these were not experienced contacts, but they might broaden the findings on the meaning of the concept. Then the meaning units were grouped according to which period in the participants' illness trajectory they belonged, and were then condensed and labeled with a code. All coded data were grouped together based on their similarities and difference, and ultimately three themes were named (Björklund et al., 2009). Latent qualitative content analysis seemed to be appropriate to use since it involves an 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, family and others, and various actives (Björklund et al., 2008). The meanings unit were marked condensed and label 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 (ibid).

3.6.3 Interpretative descriptive analysis

Before the final study began (Björklund et al., 2010), 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 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. 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. The interview text was rich and deep in structure, and the researcher 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 of 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 transcripts 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 (Björklund et al., 2010).

3.6.4 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 with different stages of HNC. Additionally, for the past decade I have been a lecturer, teaching e.g. health sciences, nursing and oncology proficiency. The pre-understanding was a requirement for performing the interview studies, given the 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. 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 necessary verbal but also responses expressed in body language or in writing.

The pre-understanding about living with HNC and the concept of health promotion has changed during the research work. As a consequence, the concept of health promotion is not equivalent in the four 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 the pre-understanding could interfere with the findings, this should be taken into consideration especially regarding the concept of health promotion.

4. 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 (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 (Björklund & Fridlund, 1999). Participants in the next two studies were treated in a specific area in the southern Sweden, and it was important to act with strict confidentiality (Björklund et al., 2008; 2009; 2010). The researcher was careful not to reveal the specific diagnosis, age, gender and 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.

4.1 The principles 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 written 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 (Björklund & Fridlund., 1999). The researcher 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. All the 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 some questions or leave the study, but no participant made such request. On occasion participants asked to postpone the interview, and death precluded some interviews (Björklund et al., 2010).

4.2 The principles of beneficence and the principle of non-maleficence

When conducting qualitative research with patents who are in vulnerable life situation 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. 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.

5. Findings

The deep understanding of living with 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. Inherent in these feelings were the patients' struggle and orientation towards the health, power, and control

that offered them belief in the future. 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.

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

The researcher'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 (Bjorklund & Fridlund, 1999). The nurses engaged 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' perspective 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 (Björklund et al., 2008; 2009; 2010).

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.

5.1 Living with head and neck cancer

Some of the patients' 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. 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. 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.

(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. 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. Further, it was understood that feeling breathless made patients extremely anxious, and they were afraid of choking during sleep, and this discomfort mirrors confinement in a rouge body.

(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. The experiences of hope were most noticeable in comforting meetings with next of kin, good friends, and sometimes with health professionals that gave them emotional support.

(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, and they felt an altered sense of affiliation. It was not uncommon that they preferred to be alone and limited their social life to conserve energy, and the findings revealed this self-induced isolation. 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. Further, 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. 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. The findings showed that the patients' working life changed and feelings of harassment from employers when being on sick-leave, no consideration given to their new life situation, and feeling threatened by legal proceedings.

(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. Patients developed an existential loneliness and feelings of living in the land of the sick; an experience amplified by the patients' perceived rejection by next of kin and changed sexual relationship.

5.2 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. 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. The ability to reach goals for better health was connected to the patients' *internal* and *external enabling* to regain control and empower oneself.

5.2.1 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. 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. 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. 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. 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.

5.2.2 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. *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. 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. 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. 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. The findings revealed that if patients experienced something that suited their capability, something they found pleasurable and motivating, this *hobby and activity* created flow and 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. 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. *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. 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 and 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. Kind and considerate treatment was invaluable in contacts with health professionals and enhanced a patient's sense of autonomy. 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. 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. Further, 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. The patients wanted to be seen and respected as active persons and meet health professionals that supported their health objectives and positive potential for health rather than focusing on the disease and related problems. 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. 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.

5.3 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. Consequently, the patients' could experience hindrances to health as a lack of ability to connect to his/her (1) *internal* and (2) *external enabling*.

5.3.1 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. The changed self-image seemed to burden the patients with feelings of low self-esteem and decreased self-confidence, and these shortcomings in self-directed support could result in a self-depreciated sense of how other people viewed them, and they felt as if they were living in a compromised state. 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.

5.3.2 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.

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.

(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 and 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 limitations in human encounters. 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. 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. Contacts with health professionals that revealed hindrances against improving health were named *not-health-promoting contacts*, and were experienced predominantly before and after treatment. Still it was understood that the most important factor to patients was to be believed when expressing their illness story. 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.

6. Discussion

The findings concerned 35 individuals diagnosed with HNC, revealing their experiences of and connection with *enabling*, i.e. providing somebody with the ability or means to do something was important to their success in experiencing health and well-being and the process of taking control over of new life situation. This process of empowerment, i.e. the goal of health promotion (WHO, 1986), was an on-going 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, belief in a future, and take command over everyday life.

Living with HNC was like living on a virtual rollercoaster, 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. This corresponds to Antonovsky's (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 moving between two extremes of ease and dis-ease on the health continuum. This interpretation of *life in a symbolic roller coaster* 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 cancer forms or other chronic diseases.

An important factor could be the researchers' perspective (pathogenic or salutogenic) in interpreting the findings. Although the participants in the studies had numerous physical symptoms and experienced many 'ups and downs', they tried (and often succeeded) to repress negative feelings to make life bearable. Being positive might be part of a process where patients actively seek meaningful and therapeutic interactions with health professionals, thereby gaining important knowledge. Positive thinking could be a way to take responsibility for prevention of and recovery from cancer, i.e. one strategy to cope with cancer and its treatment (McCreaddie et al., 2010). However, it could place another burden on the already afflicted person, i.e. if you think positive enough the cancer can be cured.

For some of the patients living with HNC, the disease was understood as being 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 relationships to next of kin and/or friends. Trillin (1981) emphasized that having cancer signifies entering the land of the sick, where those from the land of the well could visit, but always leave. This corresponds to other research showing that patients on a cancer trajectory often experienced uncertainties, vulnerability, and isolation (Halldórsdóttir & Hamrin, 1997). Also, HNC causes potentially life-threatening problems, e.g. involving respiration, nose bleeding, choking while eating and swallowing, and it also causes lifelong physical problems with, e.g. altered appearance and communication (cf. Rumsey et al. 2004). No research was found that addressed the findings on patients' feelings on an altered relation to their body, which confronting them with embarrassing behaviours, e.g. phlegm stagnation resulted in a need to repeatedly clear the throat and spit. Problems seemed to have a huge impact on patients' entire everyday life and correspond to other research on HNC's bodily impact that seemed to confront patients' both a psychosocial and existential struggle (cf. Mok et al, 2010).

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. Research has shown that active memberships in patient organisation improved patients' well-being and perhaps these meetings could alleviate some of their loneliness, and help regain power and control over everyday life (Aarstad, 2008). Still, as Mok et al. (2010) point out, there is no medication for alienation, loneliness, despair, meaninglessness, and fear or 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. 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 a cheerfulness and kindness.

HNC can cause discomfort and suffering since it is located in the body's most visible area and this could either enhance personal growth or damage or destroy self-esteem (Rumsey et al. 2004). 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. (2008) 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 the individuals improved 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. Adopting new lifestyle habits required inner strength and will, and it could be valuable for health professionals to draw on these findings when following public health advice (NIPH, 2005), and start smoking cessation programmes in HNC care (Sharp, 2006), and begin to find out if patients are motivated to make lifestyle changes. The findings also correspond to the research of Mok et al. (2004) regarding patients' motivational process, process of seeking mastery, and transformation of thoughts.

The patients' often used their power of mind when meditating or praying i.e. self-transcendence are shown to be helpful in drawing on one's own strength and health resources (cf. Dossey et al., 2000). 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. 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 and 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 24 hours a day, i.e. external enablers such as next of kin or friends, were essential. It was vital to have someone to talk to, and perhaps particularly when patients experienced new illness and acute, life-threatening problems. 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. Carnevali & Reiner, 1990). The findings also support this, revealing strained relationships and changed life situations for the 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 in the studies. For example Carnevali & Reiner (1990) confirm that relationships and intimacy seem to be more important for women to discuss. These problems might relate to the patients' problems with phlegm production or mouth odour, which both parties could experience as unpleasant. It is known that this cancer could be experienced as more traumatic than other cancers because of the visible disfigurement involved (cf. Vickery et al., 2003). 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. 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. The findings also presented various confirmations on the importance of long-term support for next of kin. Co-operative care seems to alleviate fear by providing self-care education in a home setting, and 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). 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 and these 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. 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 and could lead to feelings of better health and well-being.

All the patients 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. The link between nature, health, and healing are well-known and 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 (cf. Björklund, 2010). This means a responsibility for health care to creating an atmosphere that is pleasing for the eyes, and combining this with easy access or views to parks and green spaces, since it enhances everyone's wellbeing (patients, next of kin, and health professionals).

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. This corresponds to other research showing, e.g. that art therapy could decrease anxiety and facilitate recovery and the use of music enhance effects of analgesics, and decrease pain, anxiety, and depression (cf. Leddy, 2003).

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* (Björklund & Fridlund, 1999) or *health promoting contact* (Björklund et al., 2009). In this context, the patients experienced health professionals to be available, engaged, respectful, and validating and to express knowledge, competence, solicitude, and understanding. Good interpersonal relationship between the patient and health professionals can be seen as both 'means and end' in an interaction/contact (cf. Halldórsdóttir & Hamrin, 1997). 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, 2006). 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. 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 health-care 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 (IOM, 2000).

To improve the organisation of HNC care, it should develop in teamwork with patient organisations, health professionals, and policy makers (cf. NIPH, 2005). Patient organisations are vital because of their potential influence as the voice for an entire group of patients. It can raise demands on behalf of their members, who have less opportunity to speak up in society due to the impact of the illness on their ability to communicate (Aarstad, 2008).

It is, however, known that these patients often have long-lasting and slowly progressing health problems. In addition the findings showed lack of individual, tailored care outgoing 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. This highlights a) the need for easy access to care with a salutogenic focus 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 (cf. Larsson, 2006). Rehabilitation services should also involve any next of kin engaged in a patient's everyday life and care.

The findings also indicated that the patients experienced many *not health promoting contacts* (Björklund et al., 2009) and a *lack of health promoting activities* (Björklund & Fridlund, 1999). 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. These findings correspond to the research by Halldórsdóttir & Hamrin (1997) about caring versus uncaring. When patients perceived that nurses were incompetent in some way; nonchalant or uninterested in the patient's competence, this created an obstacle in the patients' well-being and recovery. 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 information in a series of processes along with the cancer trajectory (cf. Thorne, 2006). Patients want health professionals to openly share bad and uncertain information, however to do it sensitivity. A recommend approach was to follow up uncertain or bad news with slightly better information to avoid of 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. Feber (2000) highlight the dynamic and context-specific nature of communication, and research shows the complex communication problems that patients with HNC can experience. It is of importance for health professionals to check that the information supplied has been understood and to be ready to provide further information if necessary. Patients' experienced also being in a disadvantaged position due to their vulnerability and dependence when seeking care. Research confirms the inequity of power in health care, due to the patient's dependency, and this could be an obstacle in interpersonal relationship between patients' and health professionals (cf. Halldórsdóttir & Hamrin, 1997). Ineffective communication can lead to delay in seeking care, failure to access appropriate care, and early withdrawal from treatment (cf. Thorne, 2006). 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 Shifting 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, strategies aim to maintain hope and to distance one's self from certain aspects of authenticity. 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. HNC patients undergoing treatment wanted as much information as achievable, both good and bad, especially about the treatment and its side-effects (cf. Björklund, 2010). On the other hand, patients had express being overloaded with information that they do not understand. Research 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 (cf. Thorne, 2006). The-illness-in-foreground perspective was understood to be good in HNC context of the studies, 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 represents the patients' viewpoints, perceptions, hope, attitudes, and life experiences and 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 while others, in contrast, felt threatened by their employer and felt forced to continue working. It is well known that loss of occupational identity can be a source of significant anxiety and depression in everyday life. Further, HNC patients frequently experienced becoming unemployed because of their unique problems regarding, e.g. eating, speaking, pain, fatigue, and appearance (cf. Feber, 2000). 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 (cf. Hodges & Humphris, 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. Hence, a vital factor for patients with chronic diseases is to have a well-functioning everyday life (cf. Carnevali & Reiner, 1990).

The patients experienced social and economic strains and 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. 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 the studies 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. There is a need for society and health services 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 (Björklund, 2010).

6.1 Methodological considerations

A qualitative design was chosen and 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 reveals how the own way of thinking about health promotion developed during the research. The 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, the 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 the view towards the patients were quite objectified, i.e. a person 'within' a specific form and stage of HNC (e.g. patient with stage 4 oropharynx cancer). This

was accompanied by the 'mental image' as a nurse of these patients' common problems and needs. The 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 lifestyle (Bjorklund & Fridlund, 1999). However, the understanding about everyday life with HNC and persons' inherent capacity grew and in the later studies, the view on the concept health promotion changed. As a result, the concept shifted towards a more subjective-oriented understanding of the need to focus on the affected individuals' own experience of what promoted health and well-being. This represent a shift from the traditional 'top-down' approach to '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 situation and co-producer of his/her health- it strengthens the patient's confidence in drawing on their own resources to improve their personal health and well-being.

In focus for the studies are 35 patients with HNC. Data were collected via individual, audiotaped, 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 contact with health professionals. The questions were open-ended so the participants could speak 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. Despite some differences between the four analysis methods used, they have 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 investigation. Second, the researcher (s) developed a more structured thematic analysis of every interview searching for meaning units/codes in sub theme. Finally, the researcher(s) examined the sub themes in the context of more superior theme, all at different levels of interpretations.

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 (Polit & Beck, 2008). The central aspect is to confirm that the findings truthfully mirror the experiences and viewpoints of the participants, rather than perceptions of the researchers. The aspects undertaken to guarantee credibility 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. The first study (Bjorklund & Fridlund, 1999) 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 this article (i.e. 17 individuals from Sweden and one from each of the other four Nordic countries). Although the purpose was not to generalised or compare the findings between the 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 of 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 (cf. Feber, 2000). A weakness could be that although 54 persons were invited, 19 did not agree to participate. 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 cognitively disabled patients that could not communicate their experiences. Those who did participate 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 and contacted a nurse at the ward on their own initiative. These participants had severe speech difficulties because of surgery and tumour growth, yet they gave concise information and lengthy interviews.

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. However, the participants could talk freely about the topic, and the interviewer thoughtfully went back and forth between the questions in the guide. Every interview was 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 (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. 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. 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.

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. The small contributions from next of kin seemed to benefit; 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 experience. 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 and looking at the findings (Bjorklund &

Fridlund, 1999) and the category *the nurse showed personal consideration* and the subcategory *the nurse showed empathy*. The positive form conveyed that the patients experienced the nurse as attentive, and she respected him: *the nurse was so calm and collected and sympathetic*. The negative form conveyed that the patients experienced that the nurses lower his self-esteem by trespassing his integrity; *the nurse was too good-nature, she felt sorry for me, I didn't like it*. In Björklund et al., 2009 p. 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 of their care; *they just remit patients from one place to another*.

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

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. Further, a longitudinal approach gives you an idea about the participants' experiences over time and what it could mean for them in 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 interview (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. 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. 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 the first study is the considerable overlap between the categories, and the analysis could be done more rigorous (Björklund & Fridlund, 1999).

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. In the studies, 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. It could be successful if patients, and health professionals working in this care context, recognise the descriptions and interpretations as credible. 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. However, the core question in transferability is whether it is logic to carrying 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). An important factor in promoting transferability is the quantity of information the researcher present about the context on 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 on 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 purpose of the studies, 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 rest 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 the 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 a reasoned judgement about the extent to which the 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. However, how much should the researcher formalise and argue generalisations, or could this be left to the reader? Kvale (1996) put forward Freud's therapeutic case stories as examples for reader generalisation, since his 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 (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, and patients in the first study, the time span from diagnosis to interview varied from 4 months to 14 years. It is known that the memory can change, but people always remember the

critical incidences that occur and being stricken with cancer is an extremely traumatic experience accompanied by feelings that your whole existence is threatened (cf. Carnevali & Reiner, 1990). Flanagan (1954) asserted that the authenticity of data collected via the critical incident technique is very high since the 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.

7. Conclusions

The aims of the studies have been to reach a deeper understanding of living with HNC 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 supporting 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 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.

8. 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 are (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. 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.

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 and evaluate in this context since the model seems to be suitable 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. It 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.

9. Further research

Health and health promotion is an integral part of nursing, and maybe the findings in the studies 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 heightening 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.

More 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. Other 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 experiences 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 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 of Sense of Coherence studies (cf. Langius et al, 1995; Antonovsky, 1996) and Quality of life studies (Aarstad, 2008) and the use of a holistic needs assessment e.g. the Patients Concerns Inventory [PCI] (Rogers et al. 2009).

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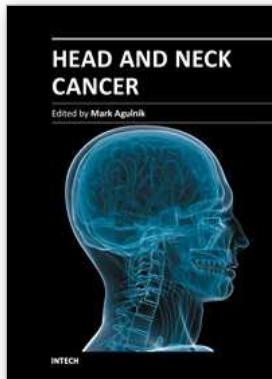
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Head and Neck Cancer provides an interesting and comprehensive overview of all aspects of head and neck cancer including overviews of the disease, basic science aspects pertaining to the disease, diagnosis, treatment and outcomes for patients with this disease. The chapters written by world renowned experts cover the entire discipline of head and neck oncology and include discussions of regional disparity is, advances in basic science understanding, advances in her radiotherapy, chemotherapy and targeted agents as well as a focus on reconstruction, prostheses, and aspects of quality of life and health outcomes. The book is designed to be both practical and comprehensive for every physician treating his complex disease.

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