Chapter 1

General Introduction
Patients who are treated for head and neck cancer (HNC) are often faced with several physical and psychological difficulties, that can have a negative effect on their quality of life. HNC patients may encounter problems with body image and sexuality, induced by possible appearance and functional changes in the head and neck area after treatment. Supportive care interventions can be provided to help them cope with these issues. However, in-depth insight into body image and sexuality and supportive care among HNC patients is scarce. In this thesis, various studies will be presented on the identification, prevalence and course of body image distress and sexual issues in HNC patients. Moreover, studies that evaluate interventions to improve these symptoms will be discussed. In this chapter, background information is provided on HNC and its treatment, followed by current knowledge on body image and sexuality in HNC patients. Additionally, evidence on supportive care interventions targeting body image and sexuality in HNC patients is discussed. The chapter is completed with the aim and outline of this thesis.

HEAD AND NECK CANCER

Epidemiology and treatment
Annually, around 3000 people are diagnosed with HNC cancer in the Netherlands. HNC is the seventh most common form of cancer in men and the ninth in women. HNC mostly originates in the oral cavity, oropharynx, hypopharynx and larynx. Other sites that can be affected by HNC are the lips, nasal cavity, nasopharynx, paranasal sinuses and salivary glands. The five-year survival rate for HNC is approximately 50% and ranges from 32% for patients with advanced cancer in the hypopharynx, up to 68% for patients with cancer in the larynx.

HNC is treated with surgery, radiation or chemotherapy, or a combination of these treatment modalities. In recent years, there is growing attention for promising biologically targeted therapies, although none have materialized into the clinic thus far. The treatment options depend on histology, TNM stage (classification of malignant tumors), tumor site, the condition of the patient, and patient and physician preferences. Early stage cancer is usually treated with surgery or radiotherapy alone, whereas advanced stage cancer usually requires a combination of treatment modalities. In some cases, major surgery is required such as removal of the larynx or parts of the upper or lower jaw. In order to obtain a functional and cosmetically adequate result of the treatment, reconstructive surgery is applied. The reconstruction options range from relatively simple surgical techniques such as primary closure of the resected region, to highly advanced techniques where bone, skin or muscles from other body parts are transferred to the head and neck area. For example, bone and skin tissue from the lower leg can be used for a reconstruction of the lower jaw and adjacent structures.
The main causes of HNC are tobacco use, excessive alcohol consumption, or combined use of tobacco and alcohol, accounting for at least 75% of all cases\(^7,8\). The incidence of HNC increases with age: most patients are diagnosed in the late fifth to eighth decade of life\(^9\). Also, HNC is more common in men than in women\(^10\), probably due to higher rates of tobacco and alcohol use among men. In recent years, smoking and drinking related HNC has dropped. However, the amount of oropharyngeal cancer patients has been increasing. This is caused by another risk factor for HNC, namely infection with high-risk human papillomavirus\(^11\). To date, HPV is present in 24.9% of patients with an oropharyngeal squamous cell carcinoma worldwide (of which 47% in the tonsils)\(^12\). HPV-positive HNC is strongly associated with a higher number of lifetime oral sex partners (>5) and vaginal sex partners (>25)\(^13\). Patients with HPV-positive HNC are likely to be younger (fourth and fifth decade of life) and male\(^12,14\) and their prognosis and quality of life is better than for HPV-negative patients\(^15,16\).

**Health-related quality of life**

HNC and its treatment can have a significant impact on a patients’ life, because it can affect several vital functions such as breathing, speaking and swallowing\(^17,18\). Other symptoms that are often reported in HNC patients are problems with nutrition, changes in taste and smell, and shoulder dysfunction. More generic treatment side effects like fatigue, pain, and insomnia can also be present\(^19\). Being faced with a life-threatening disease and having to deal with the symptoms after treatment can have psychological effects, such as depression, anxiety, and fear that the cancer will return\(^20-22\). In addition, body image and sexuality can be influenced as a consequence of the tumor and its treatment. Usually, symptoms worsen during treatment and gradually improve to baseline values after treatment\(^23\). However, some symptoms remain present in the long-term, even years after treatment\(^24\). These short- and long-term consequences can affect a patient’s health-related quality of life (HRQOL)\(^24,25\). HRQOL is defined as “a multidimensional concept that can be viewed as a latent construct which describes the physical, role functioning, social, and psychological aspects of well-being and functioning”\(^26\). This thesis will specifically focus on body image and sexuality in HNC patients.

**Body image and sexuality**

Body image is an important aspect of HRQOL that can be affected in HNC patients. Body image is defined as a multifaceted concept involving self-perceptions, thoughts, feelings and behavior regarding the entire body and its functioning\(^27-29\). Body image can be disrupted following HNC treatment, because patients often have to cope with (permanent) appearance changes in the head and neck area, that are not easily hidden from view (Figure 1-3). A surgical treatment may lead to scars, disfigurements, an affected facial contour and expression\(^28,30,31\). Some patients need a surgically created airway through the front of the
neck (tracheostomy) after removal of the larynx\textsuperscript{32}. Radiotherapy may result in swellings, fibrosis and alterations in skin pigmentation\textsuperscript{31}. Moreover, HNC treatment may result in functional loss that can negatively influence body image, such as speech and swallowing dysfunction\textsuperscript{33}. A facial disfigurement can have a tremendous impact on an individual level as well as in interaction with others. On an individual level, it can be distressing to see how one's appearance has changed and it might take some time to get adjusted to a different looking face in the mirror. It has been observed that disfigurement can threaten one's personal identity\textsuperscript{30,34}, since one's face is often considered a unique identifier\textsuperscript{35}, and provides individuals with a sense of self\textsuperscript{36}. On the interpersonal level, HNC can distort interaction with others. HNC patients report receiving unwanted attention in public like staring gazes, questions or comments about their looks\textsuperscript{34}. This stigmatizing behavior from others is associated with feelings of shame and a negative self-esteem\textsuperscript{37}. A facial disfigurement can also hinder communicating emotions and expressions, resulting in a feeling of social isolation\textsuperscript{38}. In sum, dealing with a facial disfigurement is challenging in many aspects of life. Therefore, it is not surprising that body image distress in HNC patients is highly prevalent (range 25-77\%)\textsuperscript{31}, and psychosocial adjustment to appearance changes varies considerably between HNC patients\textsuperscript{39}. Body image distress has shown to be associated with a decreased HRQOL and increased depressive symptoms\textsuperscript{27,40,41}.

![Figure 1-3. Photos for the 2018 “Make Sense” campaign from patient advocacy group (in Dutch: patiëntenvereniging) HOOFD-HALS. The theme was about a changed appearance after head and neck cancer. Their goal was to raise awareness of symptoms associated with a head and neck tumor.](image)

Related to body image, sexuality is another essential HRQOL aspect in HNC patients. Even though the reproductive organs are not affected, being diagnosed with HNC cancer is often accompanied by changes in sexuality\textsuperscript{42,43}. This is because many factors can cause sexual
changes in cancer patients. The biopsychosocial model is a framework that can be used to explain which factors determine someone's sexual health\textsuperscript{44}. First, biological influences may impact sexuality. Treatment like chemotherapy can have a damaging effect on body cells and can induce symptoms of tiredness, weakness and feeling nauseated\textsuperscript{45}. These symptoms can reduce one's ability and motivation for sex. Chemotherapy can also cause hormonal changes (e.g. lower testosterone levels), which affects one's sensitivity to sexual stimulation\textsuperscript{46,47}. Second, psychological influences play an important role in sexuality. Mood disorders like anxiety and depression are highly prevalent in cancer patients\textsuperscript{48}, which can negatively affect sexuality\textsuperscript{49}. Third, social influences can change sexuality. A cancer diagnosis can be a challenging period for patients as well as their partners. It is known from research that fear of intimacy and lack of communication between partners can induce relationship problems and corresponding sexual issues\textsuperscript{49}. Additionally, these biological, psychological and social factors also influence each other. A last cause of reduced sexuality in HNC patients that should not be ignored, are lifestyle habits. It is known that smoking, excessive alcohol use, a lack of exercise and obesity are strongly associated with erectile dysfunction in men\textsuperscript{50}. Although evidence is limited, it has also been suggested that smoking and alcohol is associated with sexual problems in women (such as dyspareunia)\textsuperscript{51-53}. Since a significant percentage of HNC patients are heavy smokers and drinkers, the relation between HNC and sexual issues can be partly explained by the patients' lifestyle. Thus, sexual issues in cancer should be studied using an integrative approach.

Sexual issues manifest themselves as changes in sexual function, activity and pleasure. There might be problems with sexual functioning, such as a decreased sexual desire and arousal. Women with cancer frequently experience pain and vaginal dryness and men with cancer can develop erectile dysfunction\textsuperscript{54}. Moreover, a decrease in the frequency of sexual behavior has been reported in HNC patients after laryngectomy (removal of the larynx)\textsuperscript{55}, and some HNC patients experience less sexual enjoyment\textsuperscript{42}. Sexual issues can lead to significant distress and have a negative effect on wellbeing\textsuperscript{45,54} and HRQOL\textsuperscript{56,57} of (head and neck) cancer patients.

Previous research put forward that less sexual interest is one of the most frequently reported quality of life problems mentioned in HNC patients\textsuperscript{42}. HNC patients encounter specific circumstances that can influence sexuality. One important aspect is the impact of facial disfigurement, which can induce the feeling that one is sexually unattractive\textsuperscript{28,58}. Moreover, treatment of HNC can affect speech or facial expression resulting in trouble with social contact and intimacy\textsuperscript{58,59}. HPV-positive HNC can contribute to concerns about sexuality, because of fear of transmitting the HPV to their partner when resuming sexual contact\textsuperscript{60}. Lastly, functional barriers can make sexual intercourse problematic. A dry mouth, trouble with opening the mouth, and a painful mouth or neck can make oral sex or kissing
A previous review showed that 24-100% of HNC patients reported a negative effect of HNC and its treatment on sexuality. Body image and sexuality have proven to influence each other in the non-cancer population. Especially feeling self-conscious and negative cognitions about one’s appearance influence sexuality in women negatively. Body image problems interfere with sexual responses, experiences and behavior. For example, taking a spectator perspective during sexual activity interrupts sexual responses, because attention is focused on one’s sexual performance rather than on sensory aspects of the sexual experience. Evidence is more limited for men, but a study from Cash and colleagues shows that less anxious/avoidant body focus was associated with better sexual functioning. In cancer populations, body image has also shown to be related to poor sexual outcomes, like less sexual satisfaction. In HNC patients however, results are inconclusive. One study among 66 post-surgery HNC patients found that the degree of disfigurement was associated with impaired sexuality. However, another study among 55 HNC patients treated with surgery or radiotherapy, found no correlation between sexual functioning and severity of disfigurement. Whether body image and sexuality are related in HNC patients and in which way they influence each other, should be further investigated.

IDENTIFYING BODY IMAGE DISTRESS AND SEXUAL ISSUES IN HNC PATIENTS

In order to improve care for HNC patients, it is essential to identify patients who are at risk of developing body image distress and sexual issues. For this purpose, patient-reported outcome measures can be used: questionnaires that measure symptoms from a patient perspective. Commonly used patient-reported outcome measures to detect body image are for example the Appearance schemas Inventory-revised or the Derriford Appearance Scale-24, however these are developed for a broad population, not specifically for cancer patients. Other questionnaires measure body image in a tumor-specific cancer population, such as breast cancer or gynecologic cancer. A patient-reported outcome measure that is widely known for measuring body image in all cancer patients, is the Body Image Scale (BIS). Since its development in 2001, it is translated and validated in several languages and can be used for detecting body image difficulties in patients with all tumor types, including HNC. However, more information is needed about the reliability and validity of this scale. Systematically reviewing the measurement properties of the BIS to measure body image issues in (HNC) patients would be valuable.

With the BIS as measurement instrument, it will be possible to gain more insight into body
image distress of head and neck cancer patients. As mentioned earlier, body image distress in HNC patients is highly prevalent. However, information is lacking on body image distress in a general sample of HNC patients, treated with different treatment modalities. A general overview is needed to provide information on how often body image distress arises and which HNC patients are at an increased risk of developing body image distress. In addition to this quantifying information, it is of importance to dive into the personal experience of HNC patients regarding their appearance changes. Qualitative research into this topic has revealed some of the struggles that HNC patients experience, among patients with an amputated facial area. It is worthwhile to learn more about body image distress among a broader population of HNC patients, to gain insight in more common bodily changes and the effects they have on thoughts and feelings towards their body.

A commonly used patient-reported outcome measure to detect symptoms of HRQOL is the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-C30. Additional EORTC questionnaires are available to measure tumor-specific symptoms. In HNC patients, the EORTC QLQ-H&N35 and the updated version HN43 measure head and neck cancer specific symptoms, including a sexuality subscale. Other commonly used patient-reported outcome measures in research to measure sexuality are the Female Sexual Function Index (FSFI) for women, and the International Index of Erectile Function (IIEF) for men. Despite the fact that it is known that sexual issues are highly prevalent among HNC patients, we lack information on when problems arise, how they develop over time and who is at risk of developing sexual issues. To answer these questions, longitudinal studies are needed that measure quality of life and sexuality in HNC patients.

**INTERVENTIONS TARGETING BODY IMAGE AND SEXUALITY IN HNC PATIENTS**

Once patients have been identified with body image or sexual concerns, appropriate supportive care could be offered to alleviate symptoms. Supportive care is referred to as the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement. Previous research has shown that HNC patients often report (unmet) needs for supportive care to address symptoms regarding body image (16-24%) and sexuality (15-38%). This is a clear signal that adequate supportive care is warranted to alleviate sexual issues and body image concerns in HNC patients.
A promising solution to support cancer patients is the growing offer of self-management interventions. Self-management includes those tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition(s)\textsuperscript{96}. By offering self-management interventions, patients are encouraged to participate in managing their own care, including treatments, lifestyle changes and diverse psychological consequences of health conditions\textsuperscript{96}.

Within the field of self-management, eHealth interventions are gaining popularity. eHealth refers to health services and information that are delivered through the internet and related technologies\textsuperscript{97}. eHealth interventions have the advantage to offer support that can be easily obtained, it is flexible and cost-effective\textsuperscript{97}. Furthermore, interventions can be used in the home situation, without interference of a health care professional\textsuperscript{96}. This may be an extra advantage for delicate topics such as sexuality, since it has been shown that patients often feel hesitant to seek face-to-face contact for sexual concerns\textsuperscript{99}. Previous research has shown that cancer patients are positive about self-management and eHealth interventions\textsuperscript{100}. Moreover, several studies demonstrated that interventions that include (components of) self-management or eHealth are feasible\textsuperscript{101-103} and can be (cost-)effective\textsuperscript{104,105} in HNC patients.

Concerning sexuality, limited interventions are available for this population to address sexual issues. However, a stepped care intervention targeting psychological distress in HNC patients, also seems to have short-term benefits for sexual well-being\textsuperscript{105}. The stepped care program includes four steps to treat psychological distress: (1) watchful waiting, (2) guided self-help via internet or a booklet, (3) face-to-face problem-solving therapy, and (4) specialized psychological interventions\textsuperscript{106}. HNC patients with psychological distress start with the first low-intensive step and enter the next step if they do not recover. A deeper exploration is needed on the effects of stepped care on sexuality on the long term, and which HNC patients benefit in particular.

Evidence for interventions targeting body image distress in HNC patients is also limited\textsuperscript{107,108}. Only one pilot study reported that a generic psychoeducational intervention had positive effects on body image in oral cancer patients\textsuperscript{107}. An example of an intervention specifically targeting body image is “My Changed Body”. This is a self-help expressive writing intervention designed to improve body image arising from a breast cancer treatment. It entails a self-paced writing activity that is based on self-compassion and stimulates self-kindness, mindful awareness and a feeling of common humanity\textsuperscript{109-111}. Recently, the intervention has proven to be more effective in reducing body image distress and improving body appreciation in breast cancer survivors in Australia, compared to unstructured expressive writing\textsuperscript{112}. It would be valuable to study the reach and effects of “My Changed Body” among HNC survivors, to discover if it can also improve body image in this population.
In conclusion, research is needed that sheds light on how to identify body image distress and sexual issues in HNC patients, as well research that evaluates interventions that might be beneficial in relieving these symptoms. The ultimate goal is to improve the quality of care, and help HNC patients when they struggle with changes in their body image and sexuality.

AIM OF THIS THESIS

This thesis investigates body image and sexuality in HNC patients. The first part of this thesis focuses on the identification and prevalence of body image distress and sexual issues in HNC patients using patient-reported outcome measures. The second part of this thesis evaluates the reach and effect of supportive care interventions on body image and sexuality targeting HNC patients.

Outline

The first part of this thesis (Chapter 2, 3 and 4) concerns the identification of body image and sexuality issues in HNC patients. Chapter 2 provides a review of the measurement properties of the BIS. Next, Chapter 3 describes the prevalence of body image distress and its associated factors in HNC survivors, including a qualitative overview of experiences that evoked body image distress. Chapter 4 presents the course of sexuality and its associated factors in HNC patients treated with primary (chemo)radiotherapy. The second part of this thesis (Chapter 5 and 6) discusses supportive care interventions that could alleviate body image distress and sexual issues. Chapter 5 provides insight into the efficacy of the “Stepped care” intervention targeting psychological distress for sexual well-being. Chapter 6 reveals the results of a pilot study investigating the intervention “My Changed Body” to improve body image in HNC survivors. In Chapter 7, this thesis ends with a general discussion on the studies described in the previous chapters, their strengths and limitations, clinical implications and suggestions for future research.
REFERENCES


