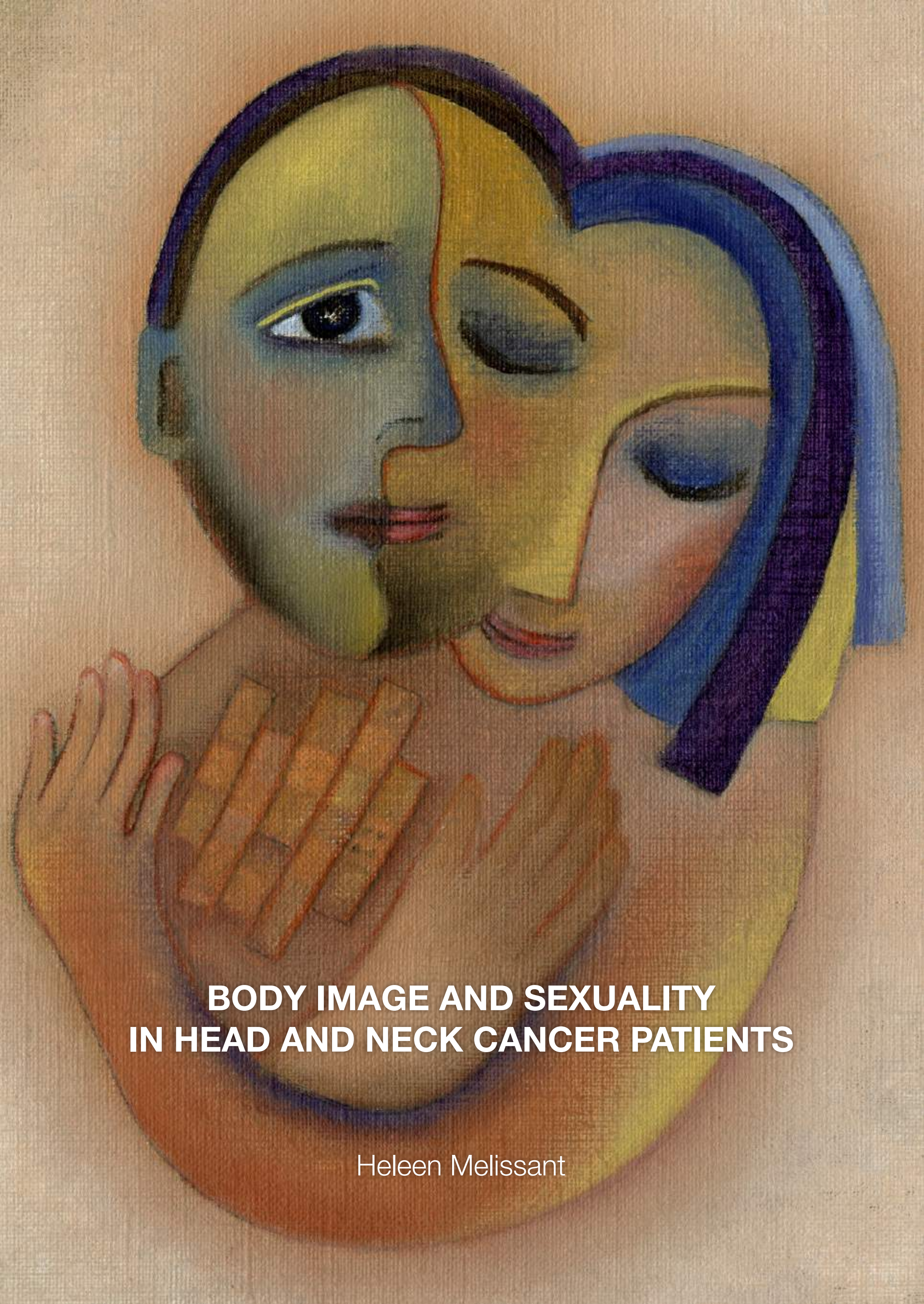

BODY IMAGE AND SEXUALITY IN HEAD AND NECK CANCER PATIENTS

Heleen Melissant

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Het ontwerp van de schildering in geïnspireerd door de kubistische portretten van Pablo Picasso. Kenmerkend van deze stijl is dat vormen uiteenvallen in fragmenten. Het gelaat van de man laat zowel hoop en positiviteit zien, als ook onzekerheid; hij heeft littekens in de hals. De positiviteit wordt versterkt door de liefdevolle omarming van zijn partner.

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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[1]. 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%[2] and ranges from 32% for patients with advanced cancer in the hypopharynx, up to 68% for patients with cancer in the larynx[1].

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[2]. The treatment options depend on histology, TNM stage (classification of malignant tumors), tumor site, the condition of the patient, and patient and physician preferences[3]. Early stage cancer is usually treated with surgery or radiotherapy alone, whereas advanced stage cancer usually requires a combination of treatment modalities[3]. 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[4]. 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[5]. For example, bone and skin tissue from the lower leg can be used for a reconstruction of the lower jaw and adjacent structures[6].

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[32]. Radiotherapy may result in swellings, fibrosis and alterations in skin pigmentation[31]. Moreover, HNC treatment may result in functional loss that can negatively influence body image, such as speech and swallowing dysfunction[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[30,34], since one's face is often considered a unique identifier[35], and provides individuals with a sense of self[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[34]. This stigmatizing behavior from others is associated with feelings of shame and a negative self-esteem[37]. A facial disfigurement can also hinder communicating emotions and expressions, resulting in a feeling of social isolation[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%)[31], and psychosocial adjustment to appearance changes varies considerably between HNC patients[39]. Body image distress has shown to be associated with a decreased HRQOL and increased depressive symptoms[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.

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[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[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[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[46,47]. Second, psychological influences play an important role in sexuality. Mood disorders like anxiety and depression are highly prevalent in cancer patients[48], which can negatively affect sexuality[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[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[50]. Although evidence is limited, it has also been suggested that smoking and alcohol is associated with sexual problems in women (such as dyspareunia)[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[54]. Moreover, a decrease in the frequency of sexual behavior has been reported in HNC patients after laryngectomy (removal of the larynx)[55], and some HNC patients experience less sexual enjoyment[42]. Sexual issues can lead to significant distress and have a negative effect on wellbeing[45,54] and HRQOL[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[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[28,58]. Moreover, treatment of HNC can affect speech or facial expression resulting in trouble with social contact and intimacy[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[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 problematic[61,62]. A previous review showed that 24-100% of HNC patients reported a negative effect of HNC and its treatment on sexuality[58].

Body image and sexuality have proven to influence each other in the non-cancer population[63]. Especially feeling self-conscious and negative cognitions about one's appearance influence sexuality in women negatively[64]. 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[65] 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[63,66,67]. 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[68]. However, another study among 55 HNC patients treated with surgery or radiotherapy, found no correlation between sexual functioning and severity of disfigurement[69]. 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[70] or the Derriford Appearance Scale-24[71], 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[72,73]. A patient-reported outcome measure that is widely known for measuring body image in all cancer patients, is the Body Image Scale (BIS)[74]. 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[75-80]. However, more information is needed about the reliability and validity of this scale[81]. 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[31]. 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[34,82,83]. 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[84,85]. 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[86,87], 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[88], and the International Index of Erectile Function (IIEF) for men[89]. 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”[90,91]. Previous research has shown that HNC patients often report (unmet) needs for supportive care to address symptoms regarding body image (16-24%)[27,92,93] and sexuality (15-38%)[92-94]. 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)[95]. 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[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[97]. eHealth interventions have the advantage to offer support that can be easily obtained, it is flexible and cost-effective[97]. Furthermore, interventions can be used in the home situation, without interference of a health care professional[98]. 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[99]. Previous research has shown that cancer patients are positive about self-management and eHealth interventions[100]. Moreover, several studies demonstrated that interventions that include (components of) self-management or eHealth are feasible[101-103] and can be (cost-)effective[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[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[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[107,108]. Only one pilot study reported that a generic psychoeducational intervention had positive effects on body image in oral cancer patients[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[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[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.

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Chapter 2

A systematic review of the measurement properties of the Body Image Scale (BIS) in cancer patients

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ABSTRACT

Introduction

Body image is acknowledged as an important aspect of health-related quality of life in cancer patients. The Body Image Scale (BIS) is a patient-reported outcome measure (PROM) to evaluate body image in cancer patients. The aim of this study was to systematically review measurement properties of the BIS among cancer patients.

Methods

A search in Embase, MEDLINE, PsycINFO, and Web of Science was performed to identify studies that investigated measurement properties of the BIS (Prospero ID 42017057237). Study quality was assessed (excellent, good, fair, poor), and data were extracted and analysed according to the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) methodology on structural validity, internal consistency, reliability, measurement error, hypothesis testing for construct validity, and responsiveness. Evidence was categorized into sufficient, insufficient, inconsistent, or indeterminate.

Results

Nine studies were included. Evidence was sufficient for structural validity (one factor solution), internal consistency ($\alpha = 0.86$–0.96), and reliability ($r > 0.70$); indeterminate for measurement error (information on minimal important change lacked) and responsiveness (increasing body image disturbance in only one study); and inconsistent for hypothesis testing (conflicting results). Quality of the evidence was moderate to low. No studies reported on cross-cultural validity.

Conclusion

The BIS is a PROM with good structural validity, internal consistency, and test-retest reliability, but good quality studies on the other measurement properties are needed to optimize evidence. It is recommended to include a wider variety of cancer diagnoses and treatment modalities in these future studies.

INTRODUCTION

Patients with cancer are often faced with invasive treatments, with a temporal or permanent impact on appearance. Cancer patients may have to deal for example with scars or amputated body parts following surgery, skin burns due to radiation therapy, or hair loss due to chemotherapy. These appearance changes can negatively affect body image. Body image is a multi-dimensional construct and comprises cognitive, behavioral, and affective aspects of appearance[1]. For instance, altered body appearance after cancer treatment can be accompanied with feelings of shame, negative self-esteem, or social avoidance[2,3]. For some patients, negative aspects of body image are persistent and remain prevalent years after treatment[4,5] and can negatively impact quality of life. Therefore, body image is considered to be an essential factor of health-related quality of life (HRQOL) in cancer patients[6,7]. Monitoring HRQOL (including body image) in clinical practice is important to identify patients who may benefit from supportive care, and patient-reported outcome measures (PROMs) are often used for that purpose[8,9].

The Body Image Scale (BIS) is a PROM developed to measure body image in all types of cancer patients. This is in contrast to other PROMs that aim to measure body image in non-cancer populations (e.g. Appearance Schemas Inventory-Revised (ASI-R))[10] or in cancer patients with specific types of cancer or treatment (e.g. Breast Impact of Treatment Scale (BITS) in breast cancer patients, Sexual Adjustment and Body Image Scale (SABIS-g) in gynecologic cancer patients, and Body Image Screener for Cancer Reconstruction (BICR) for patients after breast reconstruction)[11-13]. The initial development and validation study of the BIS showed good measurement properties concerning internal consistency, known-group comparison and responsiveness among English-speaking breast cancer patients[14]. Since then, the BIS was validated in several other languages such as Dutch, Greek, and Portuguese[15-17] and across diverse cancer populations, e.g. in advanced cancer patients and colorectal cancer patients[18,19]. Recently, Muzzatti et al. (2017) presented a review of PROMs measuring body image in cancer patients, including the BIS, and concluded that the measurement properties of these PROMs require more thorough investigation[20]. With respect to the BIS specifically, they concluded that the measurement properties were adequate, except for inconsistent results regarding structural validity and lacking evidence for criterion validity. However, not all measurement properties were taken into account (i.e., measurement error and responsiveness). Moreover, no guideline was used to interpret results, and the methodological quality of the extracted studies was not assessed. Therefore, the aim of this current study was to conduct a systematic review specifically focusing on the measurement properties of the BIS in cancer patients, following the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) methodology.

The COSMIN methodology is based on taxonomy and definitions of measurement properties for PROMs[21] including content validity, structural validity, internal consistency, cross-cultural validity, reliability, measurement error, criterion validity, hypotheses testing for construct validity, and responsiveness. The current study will add important information to the previous review[20], which is of high importance when considering the use of the BIS in clinical trials and practice as well as for interpretation of BIS outcomes.

METHODS

The Body Image Scale

The 10-item Body Image Scale was developed by Hopwood et al. in 2001 to measure affective, behavioral, and cognitive body image symptoms. Patients can indicate body image symptoms on a 4-point scale (“not at all” to “very much”). The total score ranges from 0 to 30 and can be calculated by summing up the 10 items. A higher score means a higher level of body image disturbance[14].

Literature search strategy

This study was part of a larger systematic review (Prospero ID 42017057237)[22], investigating the validity of 39 PROMs measuring quality of life of cancer survivors included in an eHealth application called “Oncokompas”[23-25]. Before the actual search, a search for reviews and meta-analyses of the measurement properties of each of the 39 PROMs was performed. This search did not yield any relevant results for the BIS.

The databases Embase, MEDLINE, PsycINFO, and Web of Science were systematically searched for publications directly investigating aspects of measurement properties of the BIS. Search terms were the measurement instrument’s name and its acronym, combined with search terms (text words and key words) for cancer, and a precise filter for measurement properties[26] (Supplementary File S1). The search was performed in July 2016 and updated in July 2017 to verify new publications. Search results were checked for duplications.

Inclusion and exclusion criteria

Studies were included that reported on original data about at least one measurement property as defined in the COSMIN taxonomy[21] related to the BIS. Validation studies of other PROMs that reported original data on the BIS (as comparison instrument) were also included. The COSMIN taxonomy[21] distinguishes nine measurement properties for PROMs: (1) structural validity (degree to which scores of a PROM are an adequate reflection of the dimensionality of the construct to be measured), (2) internal consistency (degree of interrelatedness among items), (3) reliability (the extent to which scores for patients who have not changed are the same for repeated measurement under several conditions), (4) measurement error (systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured), (5) hypothesis testing for construct validity (degree to which the scores are consistent with hypotheses on known-groups comparison, and on relations to scores of other PROMs (convergent and divergent validity)), (6) criterion validity (degree to which the scores are an adequate reflection of a gold standard), (7) responsiveness (the ability of a PROM to detect change over time in the construct to be measured), (8) cross-cultural validity (degree to which the performance of the items on a translated or culturally adapted PROM are an adequate reflection of the performance of the items of the original version), (9) content validity (degree to which the content of a PROM is an adequate reflection of the construct to be measured). In the present review study, we did not evaluate content validity because no protocol existed to evaluate this measurement property.

We excluded studies that were conference proceedings, studies without full-text available, publications in other languages than English, and studies that investigated populations without cancer. Full-text publications were reviewed by two independent raters (KN and FJ). Disagreements regarding inclusion and exclusion were discussed until consensus was reached.

Data extraction

Two independent extractors (KN and FJ) who identified eligible studies extracted information on each of the measurement properties defined in the COSMIN taxonomy[21]. Relevant data included the study population, sample size, the method, information on missing values, type of measurement property, and its outcome. Disagreements were discussed until consensus was reached.

Data analyses

Data analyses were performed in three steps to accomplish adequate interpretation of the results, following the COSMIN methodology[27].

First, we rated the methodological quality of the included studies, based on the COSMIN checklist for assessing the methodological quality of studies on measurement properties[28]. Methodological aspects regarding design requirements and preferred statistical methods, specific to the measurement properties under consideration were rated on a 4-point scale: "excellent", "good", "fair", or "poor". In accordance with COSMIN recommendations, overall methodological quality per measurement property of the BIS was obtained by taking the lowest rating of any of the methodological aspects assessed[29].

Second, criteria for good measurement properties were applied to the results of the included studies, following the COSMIN guidelines for systematic reviews of PROMs[27,30]. Each measurement property in each individual study was rated as “sufficient” (+), “insufficient” (–), or “indeterminate” (?). For example, hypothesis testing for construct validity is rated as “sufficient” if at least 75% of the results are in accordance with the hypotheses. These results were qualitatively summarized to obtain an overall rating of the measurement property across all included studies: sufficient (+), insufficient (–), inconsistent (±) or indeterminate (?). If all studies indicated sufficient or insufficient results, the overall rating was accordingly. If there were inconsistencies between studies, explanations were explored. If no explanations were found, the overall rating would be inconsistent. The overall rating would be indeterminate if not enough information was available[27].

In the third step, this overall rating of evidence was supplemented by a level of quality of the evidence, using a modified Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach from the COSMIN methodology to grade the confidence in the total body of evidence available for the measurement properties[27]. Quality of the evidence was graded as high, moderate, low, or very low. This grade was based on (i) risk of bias, (ii) indirectness, (iii) inconsistency of results, and (iv) imprecision of studies. Each study was rated by a single rater (HM), whose ratings were checked by a second independent rater (KN). Discrepancies in ratings were discussed until consensus was reached.

RESULTS

Search results

In total, 980 non-duplicate abstracts were screened, of which 208 abstracts concerned the BIS. The 2017 search update resulted in 16 extra abstracts on the BIS. Having applied inclusion and exclusion criteria, 177 studies were excluded after title/abstract screening. Of the remaining 47 studies, 37 were excluded after full-text screening and one was excluded during data extraction. In total, we included nine studies that investigated measurement properties of the BIS in cancer patients (see Figure 1).

Study characteristics

Table 1 summarizes the characteristics of the included studies. One study described the development and validation of the BIS in English[14]. Six studies examined validity of the translated BIS in other languages (Greek, Spanish, Korean, Portuguese, Dutch, and Turkish)[15-17,31-33]. In one study, screening of body image in patients with advanced cancer (locally advanced, recurrent, or metastatic) was specifically the focus[18]. One study validated the BIS in colorectal cancer patients undergoing surgery[19]. The study populations were breast cancer patients[14,17,33], colorectal cancer patients[19], patients with an ostomy (included because 82% of the population were cancer patients)[32], or a mixed cancer population (including breast, gynecological, gastro-intestinal, genitourinary, head and neck, hematologic, and respiratory cancer)[18,31]. We report on the results based on data extracted from nine studies addressing structural validity, internal consistency, reliability, hypothesis testing for construct validity, and responsiveness. Although none of the studies reported on measurement error, this could be calculated for three studies. None of the studies presented results on cross-cultural validity or criterion validity.

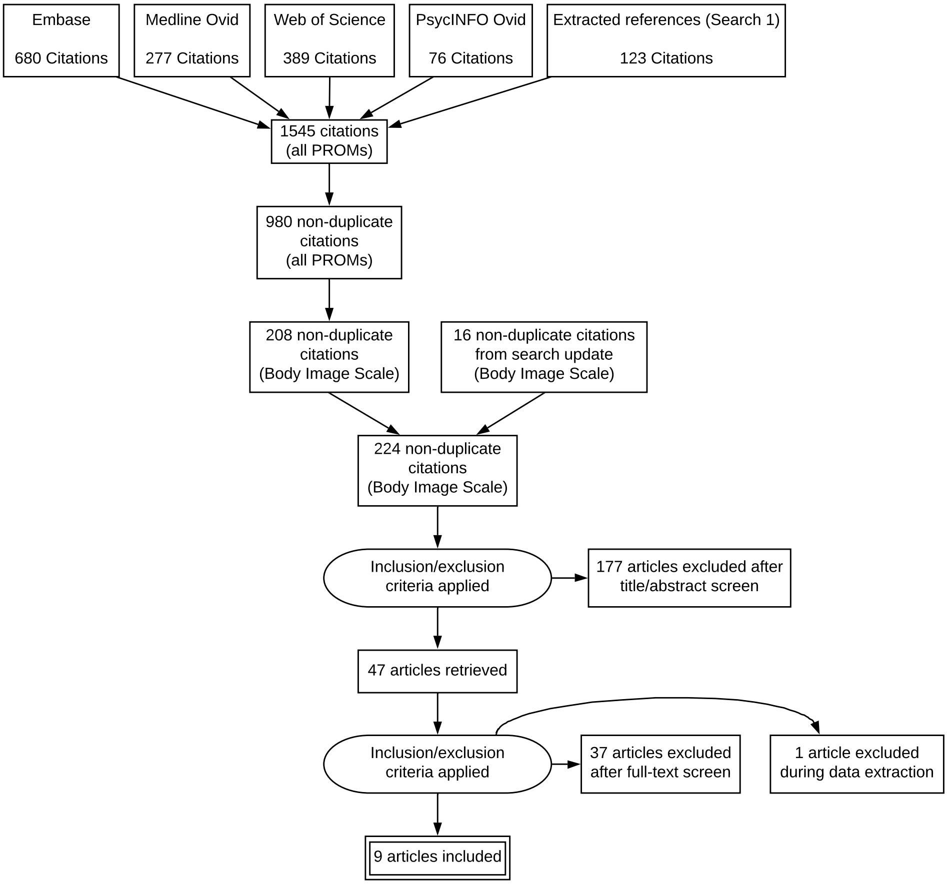

Figure 1. Flow diagram of the systematic search.

Table 1. Characteristics of included studies.

Reference	Main aim of study	Population	Sample size
Anagnostopoulos et al.[16]	Examining reliability and validity of Body Image Scale in Greek	Breast cancer patients treated with mastectomy or breast-conserving surgery; Greece	70
Gómez-Campelo et al.[31]	Validation of Body Image Scale in Spanish	Breast and gynecological cancer patients; Spain	100
Hopwood et al.[14]	Development and validation of Body Image Scale in English	Breast cancer patients; United Kingdom	682
Karayurt et al.[32]	Validation of Body Image Scale in Turkish	Ostomy patients; Turkey	100
Khang et al.[33]	Validation of Body Image Scale in Korean	Breast cancer patients treated with mastectomy, breast-conserving surgery or oncoplastic surgery; South Korea	155
Moreira et al.[17]	Validation of Body Image Scale in Portuguese	Postoperative breast cancer patients; Portugal	173
Rhondali et al.[18]	To examine the construct of body image dissatisfaction and its measurement using a single question in patients with advanced cancer	Advanced cancer patients; United States	81
Van Verschuer et al.[15]	Validation of Body Image Scale in Dutch	Breast cancer patients who have received breast-conserving treatment or mastectomy; The Netherlands	209
Whistance et al.[19]	Validation of Body Image Scale for colorectal patients undergoing surgery	Colorectal cancer patients undergoing surgery; United Kingdom	82

Measurement properties

Structural validity

In total, seven studies examined structural validity using exploratory factor analyses (EFA)[14,16,17,19,31-33] and three studies performed an additional confirmatory factor analysis (CFA)[16,31,32] (Table 2). Two studies of excellent[14] and good[33] quality concluded that, over the total study sample, the BIS has a one-factor solution. In subgroup analyses, a two-factor structure was found among breast cancer patients after mastectomy[14] and breast cancer patients after surgery with immediate breast reconstruction[33]. Three fair quality studies also reported a one-factor solution[17,31,32] and one fair quality study reported a two-factor solution[16] among breast cancer patients after breast-conserving surgery (BCS) or mastectomy. In the poor quality study[19], a multi-trait item analysis was performed.

Based on these findings, structural validity of the BIS overall was rated sufficient (+) because two studies of at least good quality and three studies of fair quality support unidimensionality of the scale. It should be noted that in some studies, a two-factor solution was also found. The quality of evidence of structural validity was graded as moderate due to inconsistent findings.

Table 2. Structural validity of the BIS.

Reference	Methodology	Results	Methodological quality	Rating
Anagnostopoulos et al.[16]	EFA[a], CFA[b]	Two factor solution: perceived attractiveness accounting for 52.7% of the variance, and body appearance satisfaction accounting for 8.4% of the variance. The two factors were positively intercorrelated (r = 0.81). Fit statistics were adequate. RMSEA: 0.058; SRMR: 0.069; CFI: 0.95.	Fair	–
Gómez-Campelo et al.[31]	EFA, CFA	One factor solution accounting for 81.03% of the variance with acceptable fit statistics. SRMR: 0.059.	Fair	+
Hopwood et al.[14]	EFA	One factor solution in three analyses accounting for 50.1-57.6% of variance. Two-factor solution for mastectomy subgroup: appearance/attractiveness (26.9% of variance) and body satisfaction (18.8% of variance) but results were not reproducible.	Excellent	+
Karayurt et al.[32]	EFA, CFA	One-factor solution, fit statistics were acceptable. SRMR: 0.05; CFI: 0.96.	Fair	+
Khang et al.[33]	EFA	One-factor solution for global (66.6% of variance), BCS (59.9% of variance) and mastectomy (74.4% of variance) subgroups. Two-factor solution for oncoplastic subgroup (40.2% and 28.6% of variance).	Good	+
Moreira et al.[17]	PCA[c]	One-factor solution with eigenvalue of 6.12, explaining 61.2% of variance.	Fair	+
Whistance et al.[19]	Multi-trait item scaling	One-factor solution single items each correlated well with the overall ten-item BIS scale with the exception of item 10 (r = 0.39). Removal of this item improved the scaling. Factor analysis suggested a one-factor solution, but item 10 had the lowest factor loading (0.41). This analysis was also repeated with item 10 excluded, and the factor loadings of the remaining nine items improved.	Poor	?

+ Sufficient, *?* Indeterminate, – Insufficient, *NA* not applicable, *RMSEA* Root mean square error of approximation, *SRMR* Standardized root-mean-square residual, *CFI* Comparative fit index, *BCS* breast-conserving surgery

[a] Exploratory Factor Analysis.

[b] Confirmatory Factor Analysis.

[c] Principal Component Analysis.

Internal consistency

All nine included studies reported on internal consistency using Cronbach's alpha (α) (Table 3). In the excellent and good quality studies, values ranged between α = 0.86–0.96[14,15,19,33]. These results are sufficient for internal consistency (α ≥ 0.70 and ≤ 0.95)[27], although in one mastectomy subgroup, a value of α = 0.96 was presented, which might reflect overlap of items within the scale. Five studies had fair methodological quality since missing items were not described. Of these studies, four showed sufficient internal consistency[16-18,32] and one[31] showed insufficient results because of values of α = 0.97 in all subgroups.

Based on these findings, internal consistency of the BIS overall was rated as sufficient (+) and the quality of evidence of internal consistency was graded as moderate because there is moderate evidence for the unidimensionality of the scale.

Table 3. Internal consistency (Cronbach's α) of the BIS.

Reference	(Sub)groups	Value (α)	Methodological quality	Rating
Anagnostopoulos et al.[16]	Satisfaction subscale (7 items)	0.87	Fair	+
	Attractiveness subscale (3 items)	0.92		
	General body image concerns (5 items)	0.81		
Gómez-Campelo et al.[31]	Total sample	0.97	Fair	–
	Breast cancer subgroup	0.97		
	Gynecological cancer subgroup	0.97		
Hopwood et al.[14]	Total sample	0.93	Excellent	+
	BCS subgroup	0.91		
	Mastectomy subgroup	0.91		
	Remaining subgroups [a]	0.86		
Karayurt et al.[32]	Total sample	0.94	Fair	+
Khang et al.[33]	Total sample	0.94	Good	+
	BCS subgroup	0.92		
	Mastectomy subgroup	0.96		
	Oncoplastic surgery subgroup	0.92		
Moreira et al.[17]	Total sample	0.93	Fair	+
	BCS subgroup	0.93		
	Mastectomy subgroup	0.92		
Rhondali et al.[18]	Total sample	0.88	Fair	+
Van Verschuer et al.[15]	Total sample (Time 1)	0.91	Good	+
	Total sample (Time 2)	0.92		
Whistance et al.[19]	Total sample (9-item scale)	0.90	Good	+

BCS breast-conserving surgery

[a] Breast cancer patients, advanced breast cancer patients, breast cancer patients with oncoplastic surgery, genetic high risk women following bilateral prophylactic mastectomy

Reliability

Four studies examined test-retest reliability. The good and fair quality studies reported values of $r = 0.92$[15] and $r = 0.85$[32], indicating sufficient results. Two studies had poor quality and therefore indeterminate results, because the time interval was considered too long (6 months compared to 2 weeks in the other studies)[33] and because of a small sample size (n = 19)[19], reporting values of ICC = 0.67 and $r = 0.89$, respectively. The low value of 0.67 may be an underestimation of the true reliability because of the long time interval. Hence, reliability of the BIS overall was rated as sufficient (+). The quality of evidence of reliability was graded as moderate because three out of four studies reported Pearson/Spearman's correlation coefficients[15,32,33], while an intraclass correlation coefficient (ICC) would have been more appropriate.

Measurement error

Although measurement error was not reported in the included studies, we were able to calculate the standard error of measurement (SEM) and the smallest detectable change (SDC) in three studies reporting reliability data and standard deviations. Two studies of good[15] and fair quality (n = 40)[32] had an SDC of 4.7 (SEM = 1.7) and 9.1 (SEM = 3.3), respectively. The poor quality study because of the large time interval between the measurements had an SDC of 11.1 (SEM = 4.0)[33]. Interpretation of measurement error is only possible if a SDC score is compared with data on minimal important change (MIC), but this was not reported. Based on these findings, measurement error of the BIS overall was graded as indeterminate (?).

Hypothesis testing for construct validity

Known-groups comparison

Eight studies performed known-group comparisons (Table 4). No a priori hypotheses were formulated in four studies[15,17,18,33], and in those cases, we assumed the hypothesis would be that BIS scores are higher (worse) (1) in patients who were treated with a mastectomy compared to patients treated with BCS[34] or breast reconstruction[35], (2) in younger patients compared to older patients[36], (3) in patients with a longer time since treatment[37], and (4) in patients with a stoma vs. without a stoma[38]. Two studies with good quality confirmed their hypotheses[14,19]. Out of five studies with fair quality[15-17,31,33], two studies confirmed the hypotheses[15,16]. One study had a poor quality[18] because no a priori hypotheses were formulated.

Table 4. Known-groups comparison of the BIS.

Reference	Comparison groups	Results	Methodological quality	Rating
Anagnostopoulos et al.[16]	Patients who underwent mastectomy vs. BCS vs. cancer-free women	Compared to women receiving breast-conserving surgery, women receiving mastectomy reported significantly more reduced perceived attractiveness and greater dissatisfaction with body and appearance.	Fair	+
	High vs. low social dysfunction scores	For low social dysfunction scores, there were no significant differences in general body image concerns among the three groups of women. However, for the high social dysfunction scores, women who had undergone mastectomy exhibited significantly higher scores on general body image concerns, compared to cancer-free and BCS women's scores.		
Gómez-Campelo et al.[31]	Age and time since diagnosis	Significantly higher BIS scores in younger patients. No significant relation between BIS and time since diagnosis.	Fair	–
Hopwood et al.[14]	Patients who underwent mastectomy vs. BCS	BIS scores were significantly higher in patients who were treated with mastectomy than those treated with BCS.	Good	+
	Age	Significantly higher BIS scores in younger patients		

Table 4 continued.

Reference	Comparison groups	Results	Methodological quality	Rating
Khang et al.[33]	Patients who underwent mastectomy vs. BCS vs. oncoplastic surgery	BIS scores were significantly higher in patients who were treated with mastectomy than those treated by BCS or oncoplastic surgery. However, the statistical significance was found only between the mastectomy and oncoplastic surgery subgroups.	Fair	–
Moreira et al.[17]	Patients who underwent mastectomy vs. BCS; age and time since diagnosis	BIS scores were significantly higher in patients who were treated with mastectomy than those treated with BCS. The effect size ($\eta^2 = .13$) was considered medium. No association with age and time since diagnosis.	Fair	–
Rhondali et al.[18]	Age	Significantly higher BIS scores in younger patients.	Poor	+
Van Verschuer et al.[15]	Patients who underwent mastectomy vs. BCS	BIS scores were significantly higher in patients treated with mastectomy than those treated with BCS at both assessment times. The effect size ($d = .47$) was considered moderate.	Fair	+
Whistance et al.[19]	Patients with a stoma vs. patients without a stoma	BIS scores were significantly higher in patients with a stoma than patients without a stoma.	Good	+

BCS breast-conserving surgery.

Convergent and divergent validity

Six studies reported on convergent validity with other body image-related instruments, psychological function, or HRQOL scales (Table 5). One good quality study[19] showed moderate correlation (r = 0.40 to 0.60) with a related construct but failed to confirm their hypotheses on three other constructs, indicating insufficient convergent validity. One study of fair quality[31] found moderate and high correlations ($r > 0.60$) with related constructs, indicating sufficient convergent validity. However, three other fair quality studies[16,17,33] presented low correlations ($r < 0.40$) with most of the related constructs, indicating insufficient convergent validity. The poor quality study did not formulate a hypothesis a priori[18]. None of the studies in this review examined divergent validity. Based on these findings, hypothesis testing for construct validity was rated as inconsistent (±) because although three studies showed sufficient evidence (> 75% of the hypotheses on known-groups and/or convergent validity confirmed)[14,15,31], this was contradicted by four studies showing insufficient evidence[16,17,19,33]. Moreover, studies reported inconsistent results in comparison with the same instrument (Appearance Schemas Inventory and Rosenberg Self-Esteem Scale)[17,18,33]. For this reason, and due to the lack of clearly stated a priori hypotheses, quality of evidence of construct validity was graded as low.

Table 5. Convergent validity of the BIS.

Reference	Comparison instrument	Correlations	Methodological quality	Rating
Anagnostopoulos et al.[16]	GHQ-28	BIS appearance & attractiveness scale	Fair	–
	- Social dysfunction	0.60; 0.38		
	- Anxiety/insomnia	0.40; 0.26		
	- Somatic complaints	0.54; 0.41		
Gómez-Campelo et al.[31]	RSES	-0.73	Fair	+
	BDI	0.83		
	BAI	0.56		
	EORTC QLQ-C30	-0.63		
Khang et al.[33]	BESAA	-0.30	Fair	–
	RSES	-0.12		
	HADS total	0.52		
	HADS-A	0.50		
	HADS-D	0.46		
	WHOQOL-BREF			
	- Overall QOL	-0.22		
	- General health	-0.38		
	- Physical health domain	-0.36		
	- Psychological domain	-0.32		
	- Bodily image and appearance facet	-0.31		
	- Social relationships domain	-0.25		
	- Environmental domain	-0.30		
Moreira et al.[17]	ESS	0.68	Fair	–
	DAS24	0.75		
	ASI-R self-evaluative salience	0.40		
	ASI-R motivational salience	-0.12		
	WHOQOL-BREF			
	- General health	-0.52		
	- Physical health domain	-0.42		
	- Psychological domain	-0.49		
	- Body image and appearance	-0.66		
Rhondali et al.[18]	ASI-R	0.24	Poor	?
	HADS-A	0.52		
	HADS-D	0.42		
	ESAS total symptom distress score	0.41		
	ESAS physical distress subscore	0.35		
	ESAS psychological distress subscore	0.37		
	MBSRQ Overall appearance satisfaction item	-0.44		

Table 5 continued.

Reference	Comparison instrument	Correlations	Methodological quality	Rating
Van Verschuer et al.[15]				
Whistance et al.[19]	EORTC QLQ-C30 emotion function	0.45	Good	–
	EORTC QLQ-C30 role function	<0.40 (exact data not shown)		
	EORTC QLQ-C30 social function	<0.40 (exact data not shown)		
	EORTC QLQ-C30 global quality of life	<0.40 (exact data not shown)		

GHQ-28 General Health Questionnaire-28, *RSES* Rosenberg Self-Esteem Scale, *BDI* Beck Depression Inventory, *BAI* Beck Anxiety Inventory, *EORTC QLQ-C30* European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30, *BESAA* Body-Esteem Scale for Adolescents and Adults, *HADS* Hospital Anxiety and Depression Scale, *WHOQOL-BREF* World Health Organization Quality Of Life scale-abbreviated version, *ESS* Experience of Shame Scale, *DAS24* Derriford Appearance Scale 24, *ASI-R* Appearance Schemas Inventory-revised, *ESAS* Edmonton Symptom Assessment System.

Responsiveness

Two studies reported on responsiveness. One study of good quality[14] found a significant increase in body image disturbance for the overall sample (n = 55) and for the BCS and mastectomy subgroups 2 weeks to 4 months postoperatively, indicating sufficient responsiveness. The other study had poor quality[19] because of a small sample size (n = 17) and found no change in BIS scores from before to after surgical treatment. Based on these findings, responsiveness of the BIS was rated as indeterminate (?). An overall summary of the results for every measurement property of the BIS is shown in Table 6.

Table 6. Overall rating of the results and levels of evidence of the BIS.

Measurement property	Rating of measurement property	Quality of evidence
Structural validity	+	Moderate
Internal consistency	+	Moderate
Reliability	+	Moderate
Measurement error	?	
Hypothesis testing	±	Low
Cross-cultural validity	NA	NA
Criterion validity	NA	NA
Responsiveness	?	

+ sufficient, – insufficient, ± inconsistent, *?* indeterminate, *NA* not applicable.

DISCUSSION

This systematic review evaluated the measurement properties of the BIS among nine studies identified in a literature search up to July 2017. In summary, evidence on structural validity, internal consistency, and reliability of the BIS was rated as sufficient, and the quality of evidence was moderate. Measurement error and responsiveness were rated as indeterminate, and hypothesis testing for construct validity was rated as inconsistent with a low quality of evidence. None of the studies reported on criterion validity and cross-cultural validity.

For *structural validity*, a one-factor solution was found and evidence was rated as sufficient. However, one fair quality study and subgroup analyses in two good quality studies showed a two-factor structure[14,16,33]. Hopwood et al.[14] found a two-factor structure among breast cancer patients after mastectomy, and Khang et al.[33] after surgery with immediate breast reconstruction. These two factors were labeled as “attractiveness” and “satisfaction with body”[14,16]. However, there was no agreement on which items belonged to which factors precisely. Also, the findings were inconsistent and in the study of Khang et al.[33] based on a relatively small study sample (subgroup $n < 50$). Further research is therefore needed to investigate whether the BIS is a unidimensional construct in all breast cancer patients, regardless of treatment modality.

Evidence on *reliability* was sufficient because it met the criterion of 0.70 in three out of four studies (range 0.67–0.92). The one study that found a correlation < 0.70 had a large time interval (6 months) between the two measurements and was therefore judged as having a poor methodological quality. It is known that body image symptoms can change in the first few months after cancer treatment[14], with patients reporting high deterioration and recovery trajectories[39]. Moreover, body changes (e.g. weight fluctuations or healing of wounds) can occur within half a year. A 7–14-day interval for test-retest reliability is in general considered most appropriate[30].

Measurement error was not reported in any of the included studies, but the SDC could be calculated in three studies. When only taking into account good and fair quality studies, the smallest change in score that can be detected, that is not due to measurement error, ranges between 4.7–9.1[15,32], on a total range of 0–30 of the BIS. However, these data are difficult to interpret since no information is available on the anchor points minimal important change (MIC) or minimal important difference (MID). Therefore, further research is needed to establish these anchor points on changes that are important.

Evidence on *hypothesis testing* for construct validity was inconsistent since findings for known-group comparisons and convergent validity were inconsistent. Known-group comparisons in most studies focused on body image issues related to surgical treatment (comparing breast cancer patients treated with mastectomy versus BCS). It is known that other types of treatment may also impact body appearance. For example, cancer survivors who received chemotherapy reported that hair loss and weight gain disrupted their body image[40,41]. In addition to recommendations to include other cancer populations than breast cancer patients[20], we also recommend to study construct validity of the BIS taking into account the impact of various cancer treatments on body image.

With respect to convergent validity, correlations with other body image scales were inconsistent. There were indications that consciousness of appearance (DAS24) and shame (ESS) are related with body image, with moderate to high correlations[17]. However, correlation with investment in appearance (ASI-R) was low[17,18]. Moreover, the relation with self-esteem (RSES) was inconsistent, with only one of two studies finding a high correlation[31,33]. Given these contradictory findings and the fair quality of these studies, no firm conclusions can be drawn about convergent validity of the BIS. This contradicts the conclusion of Muzzatti et al. presenting adequate convergent validity[20].

Evidence for *responsiveness* was indeterminate. Only one study of good methodological quality reported a change in BIS scores postoperatively[14], but no hypotheses were formulated on the expected magnitude of change and no comparison with another instrument was made. More research is needed about the ability of the BIS to detect change in body image symptoms over time.

A limitation of this review is that content validity was not investigated because at the time we conducted our data extraction, no protocol existed to investigate content validity through a systematic review. Recently, this protocol has become available[42]. Another limitation is that a precise filter instead of a sensitive filter was used. The precise filter was a pragmatic choice because a sensitive filter would provide too many hits to feasibly screen since the overall search encompassed 39 PROMs (Prospero ID 42017057237)[22]. There is a small possibility that validation studies of the BIS may have been missed. Lastly, the assessment of quality ratings was performed by one rater. This rating was then checked by a second independent rater, and discussed until consensus was reached. The gold standard practice is to have the assessment done by two raters independently because raters initially may have different opinions and consensus is needed.

This systematic review provides in-depth insight of the current evidence of the BIS as an instrument to measure body image in cancer patients and complements a recent review[20]. For researchers who want to further study the psychometric properties of the BIS, this paper points out future directions. With respect to reliability, this includes examining measurement error and research on minimal important change. Regarding validity, existing evidence on content validity should be summarized and new evidence is needed for cross-cultural validity. Criterion validity is impossible to assess, since a “gold standard” for assessing body image is not available. Efforts are therefore needed to reach consensus on a measure that could serve as second best. This may comprise body image scores by proxies such as health care providers with vast experience in the targeted study population. Furthermore, it would be valuable to examine structural validity on a possible two-factor structure among cancer subgroups (patients who had reconstructive surgery or amputation of a body part) more thoroughly. High-quality studies exploring convergent validity with investment in appearance (ASI-R) and self-esteem (RSES) are recommended. Finally, responsiveness should be more thoroughly investigated by formulating hypotheses for change scores in the BIS compared to change scores in other instruments. The BIS is mainly tested in a population of patients who are surgically treated for breast cancer. Further research including a wider variety of cancer patients and treatment modalities is recommended. New validation studies with a good methodological quality can further optimize evidence regarding the measurement properties of the BIS.

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SUPPLEMENTARY MATERIAL

Supplementary File S1. Search terms (Pubmed).
('Perceived Stress Scale'/de OR 'Insomnia Severity Index'/de OR 'International Index of Erectile Function'/de OR ((cancer NEAR/3 worr* NEAR/3 scale*) OR (patient NEAR/3 specifieke NEAR/3 klacht*) OR (insomni* NEAR/3 sever* NEAR/3 index*) OR (6-item NEAR/6 female NEAR/3 sexual* NEAR/3 function*) OR (5-item NEAR/6 erectile NEAR/3 function*) OR (sexual* NEAR/3 health NEAR/3 inventor* NEAR/3 men) OR (body NEAR/3 image NEAR/3 scal*) OR ((EORTC OR 'European Organization for Research and Treatment of Cancer') NEAR/6 (QLQ OR 'Quality of Life') NEAR/6 (PATSAT32 OR BR23 OR BR-23 OR CR-29 OR CR29 OR H&N25 OR HN25 OR HN-25)) OR (Caron NEAR/3 screening NEAR/3 questionnaire*) OR (Jong NEAR/3 Gierveld NEAR/3 loneliness) OR (7-item NEAR/3 dyadis NEAR/3 adjustment*) OR (vragenlijst NEAR/3 gezinskenmerken) OR (job NEAR/3 content* NEAR/3 questionnaire*) OR (vragenlijst NEAR/3 beleving NEAR/3 beoordeling NEAR/3 arbeid) OR (Alcohol NEAR/3 five-shot) OR (perceived NEAR/3 stress NEAR/3 scale*) OR (functional NEAR/3 assessment NEAR/3 cancer NEAR/3 therap* NEAR/3 endocrine) OR (breast NEAR/3 impact NEAR/3 treatment NEAR/3 scale*) OR (breast NEAR/3 reconstruction NEAR/3 satisfaction NEAR/3 questionnair*) OR (breast NEAR/3 cancer NEAR/3 patients NEAR/3 needs NEAR/3 questionnaire*) OR (stoma NEAR/3 quality NEAR/3 life NEAR/3 questionnaire*) OR (shoulder* NEAR/3 disabilit* NEAR/3 questionnaire*) OR (('CWS' OR 'SPK' OR 'FSFI-6' OR 'IIEF-5' OR 'CARON' OR 'JGLS' OR 'DAS-7' OR 'VGK-SF' OR 'JCQ' OR 'VBBA' OR 'A5S' OR 'FACT-ES' OR 'BITS' OR 'BRECON-31' OR 'BR-CNPQ' OR 'SDQ' OR 'stoma-QoL') NEAR/3 (assess* OR score* OR scale* OR questionnaire* OR inventor* OR measure*))):ab,ti) AND (neoplasm/exp OR (neoplas* OR cancer* OR oncolog* OR tumor* OR tumour OR carcino*):ab,ti) AND ('validation study'/de OR 'reproducibility'/de OR 'psychometry'/de OR 'observer variation'/de OR 'discriminant analysis'/de OR 'correlation coefficient'/de OR reliability/de OR 'sensitivity and specificity'/de OR validity/exp OR 'sensitivity analysis'/de OR 'internal consistency'/de OR 'confidence interval'/de OR (psychometr* OR reproducib* OR clinimetr* OR clinometr* OR observer-varia* OR reliab* OR valid* OR coefficient OR interna*-consisten* OR (cronbach* NEAR/3 (alpha OR alphas)) OR (item* NEXT/1 (correlation* OR selection* OR reduction*)) OR agreement OR precision OR imprecision OR precise-value* OR test*-retest* OR (test NEAR/3 retest) OR (reliab* NEAR/3 (test OR retest)) OR stability OR interrater OR inter-rater OR intrarater OR intra-rater OR intertester OR inter-tester OR intratester OR intra-tester OR interobserver OR inter-observer OR intraobserver OR intra-observer OR intertechnician OR inter-technician OR intratechnician OR intra-technician OR interexaminer OR inter-examiner OR intraexaminer OR intra-examiner OR interassay OR inter-assay OR intraassay OR intra-assay OR interindividual OR inter-individual OR intraindividual OR intra-individual OR interparticipant OR inter-participant OR intraparticipant OR intra-participant OR kappa OR kappa-s OR kappas OR (coefficient* NEAR/3 variation*) OR repeatab* OR ((replicab* OR repeat*) NEAR/3 (measure OR measures OR findings OR result OR results OR test OR tests)) OR generaliza* OR generalisa* OR concordance OR (intraclass NEAR/3 correlation*) OR discriminative OR 'known group' OR (factor* NEAR/3 (analys* OR structure*)) OR dimensionality OR subscale* OR (multitrait NEAR/3 scaling) OR item-discriminant* OR (interscale NEAR/3 correlat*) OR ((error OR errors) NEAR/3 (measure* OR correlat* OR evaluat* OR accuracy OR accurate OR precision OR mean)) OR ((individual OR interval OR rate OR analy*) NEAR/3 variabilit*) OR (uncertaint* NEAR/3 (measure*)) OR (error NEAR/3 measure*) OR sensitiv* OR responsive* OR (limit NEAR/3 detection) OR (minimal* NEAR/3 detectab*) OR interpretab* OR (small* NEAR/3 (real OR detectable) NEAR/3 (change OR difference)) OR (meaningful* NEAR/3 change*) OR (minimal* NEAR/3 (important OR detectab* OR real) NEAR/3 (change* OR difference)) OR ((ceiling OR floor) NEXT/1 effect*) OR 'Item response model' OR IRT OR Rasch OR 'Differential item functioning' OR DIF OR 'computer adaptive testing' OR 'item bank' OR 'cross-cultural equivalence' OR (confidence* NEAR/3 interval*)):ab,ti)

Chapter 3

Body image distress in head and neck cancer patients: what are we looking at?

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ABSTRACT

Purpose

To investigate the prevalence of body image distress among head and neck cancer (HNC) patients after treatment and to examine its association with sociodemographic and clinical factors, health-related quality of life (HRQOL), HNC symptoms, sexuality, self-compassion, and psychological distress. Secondly, we aim to explore daily life experiences of HNC patients regarding body image.

Methods

A cross-sectional survey among HNC patients investigated the prevalence of body image distress based on the Body Image Scale. Multivariate logistic regression analysis was applied to study associations with sociodemographic and clinical factors, HRQOL (EORTC QLQ-C30), HNC symptoms (QLQ-HN43), sexuality (FSFI-6; IIEF-5), self-compassion (SCS-SF) and psychological distress (HADS). Qualitative data from a body image writing intervention was used to explore experiences in daily life related to body image.

Results

Body image distress was prevalent in 13-20% of 233 HNC patients (survey response 45%). Symptoms of depression ($p < 0.001$), younger age ($p < 0.001$), problems with social contact ($p = 0.001$), problems with wound healing ($p = 0.013$) and larger extent of surgery ($p = 0.014$) were associated with having body image distress. This model explained 67% of variance. Writing interventions of 40 HNC patients showed that negative body image experiences were related to appearance and function, with social functioning problems described most often.

Conclusion

Prevalence of body image distress in HNC patients, using different cut-off scores, is 13-20%. Younger patients, patients after extensive surgery, and patients who had wound healing problems are most at risk. There is a significant association between body image distress and depressive symptoms and social functioning.

INTRODUCTION

Head and neck cancer (HNC) patients have to deal with a wide range of symptoms related to HNC cancer and its treatment[1]. Vital functions can be affected, such as breathing, speaking and swallowing. These functional impairments may negatively influence a patient's body image[2]. Also, appearance changes in the visible head and neck area may influence body image[3]. Surgical treatment may cause scarring, an amputated facial area, an affected facial contour and expression, or result in a tracheostomy[4-6]. Radiotherapy may induce swelling, fibrosis and alterations in skin pigmentation[5].

Body image is defined by thoughts, feelings and perceptions about the body and its functions[7]. A previous review identified nine studies that reported the prevalence of body image distress among HNC patients[5], with prevalence rates ranging from 25-77%. The lowest prevalence was found amongst patients after treatment of oral or oropharyngeal cancer[8] and the highest amongst newly diagnosed oral cancer patients[9]. Studies mainly focused on a specific HNC subsite (oral/oropharyngeal cancer) or a specific treatment modality (surgery). Information is scarce on body image distress in patients with other HNC sites, and patients treated with (combinations of) surgery, radiotherapy and chemotherapy.

Furthermore, more data are needed to understand which factors are associated with body image distress and how it affects daily life in HNC patients. Body image distress is found to be associated with decreased health-related quality of life (HRQOL) and symptoms of depression in HNC patients[10-12]. In addition, it may affect their identity and social relationships[6]. Body image distress may also be related to sexual problems, for example, because HNC patients no longer feel sexually attractive[4].

Previous qualitative research has described how patients with amputations in the face (e.g. nose or eye) experience and adjust to a changed appearance after HNC. In daily life, patients are constantly reminded of their disfigurement, evoked by painful or itching sensations or by unwanted attention from others[13]. Patients seem to gradually learn to cope with these situations[13,14]. However, insight into experiences from HNC patients with other (more common) bodily changes than an amputation, is warranted.

The first aim of this study is to investigate the prevalence of body image distress in HNC patients, and whether sociodemographic and clinical factors, HRQOL, HNC symptoms, sexuality, self-compassion, and psychological distress, are associated with body image distress. The second aim is to qualitatively analyse experiences of HNC patients that caused negative feelings about themselves and their body, and to explore thoughts and feelings that accompany these experiences. Results of this study will provide more insight in what body image distress means to HNC patients, and this will facilitate supportive care targeting HNC patients with body image distress.

METHODS

Study design and participants

This mixed methods study entailed a quantitative cross-sectional survey among HNC patients and qualitative analyses of writing using a writing intervention among patients with a need for care regarding body image.

HNC patients were invited to participate in a written survey on the prevalence of body image distress. Patients were recruited at the Department of Otolaryngology – Head and Neck Surgery of Amsterdam UMC, location VUmc. HNC patients were eligible if they (1) received treatment for HNC (all tumor sites, all treatment modalities) with curative intent; (2) completed treatment six weeks to five years prior; (3) provided written informed consent. HNC patients were excluded if they were <18 years, had cognitive impairments, were unable to read and write Dutch, or participated in a prospective cohort study[15]. From September 2018 to September 2019, eligible HNC patients received an invitation for this study from their physician.

For the qualitative part of the study, HNC patients who completed the survey and who had indicated a need for care regarding body image, were asked to participate in a separate consecutive study investigating a writing intervention that aims to reduce body image distress. HNC patients who participated signed a separate informed consent form and subsequently received the intervention (booklet or web-based version). After finishing the writing intervention, patients were asked to return (a copy of) their writings to the researcher. The intervention 'My Changed Body' is a self-paced writing activity[16] that uses theories of expressive writing[17] and self-compassion[18]. We used respondents' answers on the first writing prompt, in which they were asked to describe a negative experience that related to their changed body and to share thoughts and emotions.

The study was approved by and conducted according to regular procedures of the local ethical committee of VU University Medical Center. All participating patients provided informed consent.

Outcome measures

Clinical characteristics were retrieved from medical files. The survey included items on sociodemographic characteristics and patient reported outcome measures (PROMs).

The primary outcome was the 10-item Body Image Scale (BIS), measuring affective, behavioral and cognitive body image symptoms. It was developed for use in oncology populations[19]. Items are answered on a scale ranging from 0 'not at all' to 3 'very much'. A total score (range 0-30) can be calculated by summing up the items, with higher scores indicating a higher level of body image distress. The BIS has shown adequate psychometric properties[20] and is translated and validated in Dutch[21].

HRQOL was measured with the EORTC QLQ-C30, a cancer-specific quality of life questionnaire[22], and HNC symptoms were measured using the EORTC QLQ-HN43, a module specifically designed for HNC patients[23]. Sexuality was measured with the 6-item Female Sexual Function Index (FSFI-6)[24] for women and 5-item International Index of Erectile Function (IIEF-5)[25] for men. Patients were categorized in the 'no sexual activity' group if they reported not to have had sexual activity and intercourse in the past four weeks. Validated cut-off scores[24,25] for women (cut-off 19) and men (cut-off 21) were used to classify patients either as having reported sexual problems or not, to enable cross-gender analyses. To measure self-compassion, the 12-item Self-Compassion Scale-Short Form (SCS-SF) was used[26]. Lastly, psychological distress was measured using the total score of the 14-item Hospital Anxiety and Depression Scale (HADS), and two subscales that measure anxiety (HADS-A) and depression (HADS-D)[27]. All instruments used in this study are validated[23,26,28-31].

Statistical analyses

Descriptive statistics were generated for sociodemographic and clinical characteristics and the prevalence rate. The prevalence of body image distress was calculated using the most often used BIS cut-off points ≥ 10[19] and ≥ 8[32]. To investigate potential factors associated with body image distress (BIS cut-off point ≥ 8), logistic regression analyses were used. A multiple logistic regression model with a stepwise forward selection procedure was applied to investigate which factors were significantly associated with body image distress. Based on univariate logistic regression analyses, variables with p value for entry < 0.05 were added sequentially to the multiple regression model. Potential sociodemographic factors included age, gender, relationship status, education level, and work situation. Clinical factors included tumor site, tumor stage, HPV status, time since treatment, treatment modality, surgical reconstruction, neck surgery and extent of surgery (see Supplementary Table S1 for variable categories). Included PROMs were the EORTC QLQ-C30 summary score[33], EORTC QLQ-HN43 subscales and single items, sexuality (no activity, sexually active without- and with sexual problems), the SCS-SF total mean score, and the HADS total score and subscales.

To demonstrate a body image distress prevalence of 25% (based on need for support regarding body image distress[34]), and with a 95% confidence interval (CI) of a prevalence between 17.5-32.5%, 139 patients were needed for this study. For all analyses, a standard alpha level of 0.05 was used. Analyses were carried out using SPSS version 26 (IBM Corp., Armonk, NY).

Qualitative analysis

Thematic analyses were undertaken by two researchers trained in qualitative analysis (HM and AS)[35]. The coders first familiarized themselves with the data, then initial codes were identified, and underlying themes were explored. After reviewing initial findings, data were categorized into key issues and themes. Data were analysed individually and after each phase, findings were discussed in consensus meetings. Supplementary Table S2 presents the COREQ criteria checklist for describing and reporting the qualitative analysis procedures and findings.

RESULTS

Study sample

In total, 521 HNC patients were invited to participate in the study of which 233 patients (45%) participated. Of these patients, 76 participated in the writing intervention study, of whom 40 returned their writing. Patient characteristics are presented in Table 1.

Table 1. Patient characteristics.

Characteristics	**N (%)**	
	Total sample (n = 233)	**Qualitative sample (n = 40)** [a]
Mean age in years (SD)	67 (10.7)	66 (10.1)
Gender		
Male	154 (66)	28 (70)
Female	79 (34)	12 (30)
Married/in a relationship		
Yes	172 (74)	30 (75)
No	61 (26)	10 (25)
Education level		
Lower	47 (20)	11 (28)
Middle	111 (48)	19 (48)
Higher	75 (32)	10 (25)
Work situation		
Employed	68 (29)	11 (28)
Unemployed/retired	165 (71)	29 (73)
Tumor site		
Oral cavity	51 (22)	9 (23)
Oropharynx	57 (25)	9 (23)
Hypopharynx	12 (5)	1 (3)
Larynx	64 (28)	13 (33)
Other [b]	49 (21)	8 (20)

Table 1 continued.

Characteristics	N (%)	
	Total sample (n = 233)	**Qualitative sample (n = 40) [a]**
Tumor stage		
Stage I/II	103 (44)	14 (35)
Stage III/IV	120 (52)	23 (58)
Unknown	10 (4)	3 (8)
HPV positive (in case of oropharyngeal cancer)	40 (70)	7 (78)
Time since treatment in years (median) (IQR)	3.3 (2.2-4.5)	3.5 (2.5-4.8)
Single treatment	111 (48)	16 (40)
Surgery	62 (56)	7 (18)
Among which C02-laser	33 (53)	5 (71)
Radiotherapy	49 (44)	9 (23)
Combination treatment	122 (52)	24 (60)
Chemoradiotherapy	51 (42)	9 (23)
Surgery and (chemo)radiotherapy	70 (57)	15 (38)
Surgery and chemotherapy	1 (0.8)	0 (0)
Reconstruction [c]		
None	45 (34)	6 (27)
Primary closure	47 (35)	10 (46)
Surgery with reconstruction	41 (31)	6 (27)
Neck surgery [c]		
Yes	62 (47)	11 (50)
No	71 (53)	11 (50)
Surgery extent [d]		
Small	37 (28)	5 (23)
Moderate	30 (23)	5 (23)
Large	36 (27)	7 (32)
Very large	30 (23)	5 (23)

IQR interquartile range

[a] n = 29 had relevant quotes about their changed body

[b] Parotis n = 22, Skin tumor head-neck region n = 7, Nose and paranasal sinus n = 8, Nasopharynx n = 6, Unknown primary n = 5, Osteosarcoma n = 1.

[c] Only those patients who had a surgical treatment

[d] Small: C02-laser of vocal fold, lip excision, ear amputation, skin excision small nose tumor; Moderate: excision of sublingual/submandibular salivary gland, transoral excision, lip surgery with reconstruction, partial sinus resection, skin excision with local reconstruction, neck surgery; Large: parotidectomy with neck surgery, marginal and segmental mandibular resection, transoral excision with reconstruction, extensive sinus surgery, maxillectomy, skin excision with neck surgery or reconstruction; Very large: commando procedure, laryngectomy, lateral temporal bone surgery

Prevalence of body image distress and associated factors

The prevalence of body image distress was 13% (cut-off ≥ 10) to 20% (cut-off ≥ 8) (median = 2, IQR = 0-6). Univariate logistic regression analyses showed that age, gender, education level, treatment modality, surgery extent, EORTC QLQ-C30 summary score, all EORTC QLQ-HN43 subscales, self-compassion, and psychological distress were significantly associated with body image distress (results are in Supplementary Table S1). The multiple logistic regression model showed that five factors were significantly and independently associated with body image distress: symptoms of depression, younger age, problems with social contact, problems with wound healing and larger extent of surgery (Table 2). The model explained 67.0% (Nagelkerke R^2) of the variance in body image distress.

Table 2. Results of the multivariate logistic regression analyses.

Variable	OR (95% CI)	P-value
HADS depression	1.45 (1.19-1.77)	<0.001
Age	0.87 (0.81-0.94)	<0.001
Problems with social contact	2.82 (1.54-5.18)	0.001
Problems with wound healing	1.66 (1.11-2.48)	0.013
Surgery extent		0.014
Very large	1	
Large	0.08 (0.01-0.59)	
Moderate	0.02 (0.00-0.25)	
Small	0.22 (0.03-1.45)	

Qualitative responses

The writing in the intervention showed that negative body image experiences were related to appearance changes and (dys)function (Table 3). Categories of (dys)function included psychological, daily, social, physical and occupational functioning, and functioning in an intimate relationship[36].

Table 3. Negative experiences related to bodily changes after HNC.

Topic	Key issues	Themes
Appearance changes	Visible changes	Looking tired and worn out
		Neck is dented and mouth is asymmetric
		Severe weight loss
		Body has grown old quicker
		(Ugly) scars
		Burned skin due to radiotherapy
	Non-visible changes	Changes are invisible from the outside
Psychological functioning	Identity threat	Feeling lonely and sad after rejection as blood donor
		Feeling sad after losing typical generous laughter
		Losing trust in own body
	Shame	(Temporarily) feeling ashamed for burned skin at throat
		Changed face because of scars and edema
		Not daring to face people because of changed appearance
	Sadness, depression	Feeling depressed about losing vocal cords
		Feeling awful because of physical disability (concerning the tongue)
	Feeling bad and ugly	Praying to die right after surgery
Daily functioning	Low energy level	It takes much time to be able to function normally again
		Fatigue/sleeping much

Table 3 continued.

Topic	Key issues	Themes
Social functioning	Eating (in public)	Embarrassing situation
		Social isolation due to problems with eating, drinking and speech
		Difficulties with social activities due to problematic combination eating and talking
	Talking (in public)	Talking is bothersome because voice sounds nasal
		Getting frustrated if others cannot hear patient
		Speaking loudly in noisy environment is problematic because stoma plaster does not hold
		Slurring as a result of surgical procedure is uneasy because of alcoholic past
		Fear of talking in public after laryngectomy
		Hoarse voice is problematic
	Reaction from others	Being ignored because of unusual voice
		Others do not know how to react to uneasy situation
		Feeling stared at while doing grocery shopping
		Visitors think slime and drool from patient is filthy
		Others do not dare to ask how patient is doing
		Feeling misunderstood if others compare their fatigue with cancer-related fatigue
Physical functioning	Practicing a hobby	Physical recovery to be able to play golf again takes much effort
		Feelings of loss because patient cannot sing anymore
	Going on holiday	Considering to cut short holiday because of physical symptoms
Occupational functioning	Changes at work	Feeling rejected and superfluous
		Becoming unfit for work is heavy news
		Suspicion that cooperation is cancelled due to changed appearance
Functioning in intimate relationships	Rejection	Being let down by partner
	Conflict	Revealing illness to others without patient's consent
		Feeling like a burden to partner

Appearance changes

Some patients described visible changes in their appearance, for example having a dented neck or an asymmetric mouth. One patient explained: *"I look a bit older, around my chin some deep furrows have emerged and my lips aren't so pronounced anymore."*

Psychological functioning

Several patients put emphasis on feelings of shame, depression and feeling bad and ugly. Another issue mentioned was a threatened identity. Something that belonged to their identity was taken away, like being rejected as a blood donor, or having a typical laugh: *"In particular, I feel sad when I realize that I cannot sing anymore and that my generous laughter (the sound) is gone. I miss that enormously."*

Daily functioning

Some patients reported that bodily changes had a negative impact on their daily life, in particular regarding their energy level: *"In the beginning the energy level of my body bothered me. In my experience, it took a long time before I could function 'normally' again: sporting, working, living."*

Social functioning

Many patients wrote about the impact of their changed body on their social life. Difficulties with eating in public were frequently mentioned. It could cause embarrassing situations: *"Fluids and food come out of my nose if I don't pay close attention. This can be very bothersome, especially in company. I always need to have a handkerchief ready when I eat something."*

A related topic was talking in public. The different sound of voice (hoarse, nasal) or having a voice prosthesis caused difficulties with intelligibility, which was frustrating or shameful for some. *"Ever since the surgery, I have the feeling that I am slurring. Given my alcoholic past, I don't feel comfortable with that."*

Some patients were bothered by reactions of others to their changed body. Other people do not always know how to react to patients' changed appearance or dysfunction. *"I was in the grocery store and a boy around nine years old was staring at me. That's nothing out of the ordinary, as it happens on a daily basis. But then, he drew his mother's attention to me and she started to stare at me extensively, it was very bothersome."*

Physical functioning

For some patients, physical dysfunction complicated participation in activities or hobbies. For example, not having the physical fitness to play golf. *"It took around nine months before my physical condition was good enough to be able to golf 18 holes again. […] During that time, there are a lot of moments when you feel bad and sad."*

Occupational functioning

Some patients described how they became unfit for their occupation, or had to deal with negative consequences: *"An organization, which I already represented over 30 years, canceled the contract with me after a management change. It wasn't said that it had to do with my appearance, but I saw one of the directors look at me very critically/disapprovingly."*

Functioning in intimate relationships

A few HNC patients wrote about relationship problems. For example, a patient was let down: *"I was so sad when I was let down by my partner during my stay in the hospital. I really felt rejected."*

DISCUSSION

In this study the prevalence of body image distress among HNC patients was 13-20%. Body image distress was significantly associated with symptoms of depression, younger age, problems with social contact, problems with wound healing and larger extent of surgery. Patients who participated in a writing intervention reported that negative body image experiences are related not only to changes in appearance but also in functioning, including psychological, daily, social, physical, occupational functioning, and functioning in an intimate relationship.

The prevalence rate in this study was lower compared to previous studies in the head and neck cancer context, that range from 25-77%[5]. A wide variety of instruments (e.g. Derriford Appearance Scale, Body Image Survey, BIS) used to assess body image could explain this discrepancy. The highest prevalence in previous studies of 77% was found among newly diagnosed oral cancer patients who reported future appearance concerns in a clinical interview[9]. This may be more related to fear or expectations than existing body image problems. If only BIS outcomes are compared, comparable levels of body image distress were found[37,38]. In a study among HNC patients for instance <15% had a BIS score higher than 9[37], and in a study among female HNC patients the mean overall BIS score was 4.50[38].

Results of this study show that patient characteristics, social factors as well as psychological factors are associated with body image distress. This is consistent with a conceptual framework on causal factors, moderators and sequelae of body image in HNC patients[5]. In addition, the explained variance of the model in the present study is higher than in a previous study where disease stage, gender and depression explained 32% of the variance[9]. An explanation may be that our study included quality of life and clinical variables, suggesting that difficulties with wound healing, problems with social contact, and extent of surgery are key factors associated with body image distress.

Extent of the surgical procedure was related to body image distress in this study, in contrast with a study from Chen et al.[39] who found that the surgical procedure did not influence body image. These conflicting results could be explained by the different study sample used. Inclusion of patients treated with CO2-laser (less extensive surgery) in this study might explain lower body image distress compared to patients who had a commando procedure (a major operation involving removal of facial structures) or total laryngectomy. In the study sample of Chen et al.[39], the majority of patients received very extensive surgery: total/partial laryngectomy or oral excision with facial reconstruction.

The association between body image distress and depression in HNC patients was also found in studies among newly diagnosed HNC patients[9] and HNC patients from diagnosis until 12 weeks post-treatment[12]. Our study provides evidence that the association between body image distress and depression is also present for a longer time after treatment. Feelings of loss associated with a changed appearance may explain this association[12].

There was also a significant association between problems with social contact and body image distress. This outcome was further confirmed by the results of our qualitative analysis which showed that eating in public, talking in public and reactions from others were frequently mentioned events that triggered body image distress. A previous qualitative study among HNC patients also describes social concerns and avoiding people because of body image distress[40]. Over time, HNC patients are at risk to become socially isolated if no active coping strategies are undertaken[41]. HNC patients who have speech and eating problems report highest levels of social avoidance[2].

The qualitative analysis in this study revealed that identity was an important aspect of body image. HNC patients wrote about how bodily dysfunction, and not appearance changes, had a negative impact on their identity. For example, loss of one's own typical laughter may compromise one's identity. This may have to do with losing 'uniqueness and differentiation from relevant others'[42]. The other mentioned identity threat was being rejected as a blood donor. Belonging to a social group is important for identity[42]. The finding that identity in HNC can also be threatened by functional bodily changes, extends other research that describes identity threat in HNC patients from an appearance perspective[14].

This study revealed no relationship between body image and sexuality. This is somewhat surprising since a clear link between body image and poor sexual outcomes was found in other cancer populations[36]. Previous studies among HNC patients have reported conflicting results[43,44]. More research is warranted to unravel the relationship -if any- between body image and sexuality in HNC patients.

This study has some strengths and limitations. A strength is that we included a large sample of HNC patients, with a broad range of tumor sites and treatment modalities. However, due to the moderate response rate (45%), the results of this study should be interpreted cautiously. Another limitation is that we used the dichotomized BIS as an outcome variable, since no validated cut-off score is available. We dealt with this by using the most frequently used cut-off points (i.e. 8 and 10).

For clinical practice, it is recommended to identify HNC patients who suffer from body image distress, which can be monitored by letting patients complete PROMs when visiting the clinic. In that way, problems can be detected in a timely manner and supportive care provided as needed. Because evidence on effective supportive care targeting body image distress in HNC patients is still scarce[36], more research is needed.

Conclusions

The prevalence of body image distress among HNC patients in this study was 13-20%. Patients who are younger, those who had extensive surgery, problems with wound healing, symptoms of depression or problems with social contact are more likely to have body image distress. HNC patients had most negative body image experiences in the area of social functioning.

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SUPPLEMENTARY MATERIAL

Supplementary Table S1. Results of the univariate logistic regression analyses.

Variable	Mean (SD)	OR [95% CI]	P-value
Age		0.96 [0.93-0.99]	0.014
Gender			0.004
Female		1	
Male		0.38 [0.20-0.73]	
Married/ in a relationship			0.060
Yes		1	
No		1.94 [0.97-3.86]	
Education level			0.016
Lower		1	
Middle		0.46 [0.21-0.99]	
Higher		0.27 [0.11-0.67]	
Work situation			0.845
Employed		1	
Unemployed/retired		1.07 [0.53-2.20]	
Tumor site			0.47
Oral cavity		1	
Oropharynx		1.21 [0.48-3.06]	
Hypopharynx		1.37 [0.31-5.99]	
Larynx		0.59 [0.21-1.61]	
Other		1.41 [0.54-3.65]	
Tumor stage			0.234
I/II		1	
III/IV		1.50 [0.77-2.94]	
Time since treatment		0.94 [0.74-1.19]	0.592
Treatment modality			0.008
Surgery		1	
Radiotherapy		2.28 [0.70-7.48]	
Chemoradiotherapy		2.78 [0.88-8.75]	
Surgery plus (chemo)radiotherapy		5.58 [1.97-15.81]	
Surgery extent [a]			0.043
Very large		1	
Large		0.38 [0.12-1.13]	
Moderate		0.23 [0.06-0.83]	
Small		0.23 [0.07-0.77]	
Reconstruction			0.524
None		1	
Primary closure		1.71 [0.60-4.89]	
Surgery with reconstruction		1.75 [0.60-5.14]	
Neck surgery			0.086
No		1	
Yes		2.11 [0.90-4.94]	
HPV [b]			0.934
Negative		1	
Positive		1.07 [0.24-4.66]	

Supplementary Table S1 continued.

Variable	Mean (SD)	OR [95% CI]	P-value
EORTC QLQ-C30 summary score [c]	84 (14)	0.45 [0.34-0.59]	<0.001
EORTC QLQ-HN43 [c]			
Fear of progression	23 (23)	1.46 [1.26-1.69]	<0.001
Dry mouth and sticky saliva	33 (30)	1.19 [1.07-1.32]	0.001
Pain in the mouth	14 (19)	1.32 [1.13-1.54]	<0.001
Problems with senses	19 (27)	1.15 [1.03-1.28]	0.012
Problems with shoulder	15 (26)	1.22 [1.10-1.37]	<0.001
Skin problems	11 (18)	1.22 [1.04-1.43]	0.017
Social eating	16 (25)	1.28 [1.14-1.44]	<0.001
Speech	22 (26)	1.25 [1.12-1.40]	<0.001
Swallowing	15 (21)	1.29 [1.12-1.48]	<0.001
Problems with teeth	16 (23)	1.24 [1.08-1.41]	0.002
Coughing	21 (28)	1.20 [1.08-1.34]	0.001
Swelling in the neck	10 (22)	1.17 [1.03-1.33]	0.015
Neurological problems	22 (31)	1.16 [1.06-1.28]	0.002
Trismus	19 (29)	1.21 [1.10-1.34]	<0.001
Problems with social contact	4 (15)	1.62 [1.30-2.03]	<0.001
Weight loss	10 (24)	1.18 [1.06-1.33]	0.004
Problems with wound healing	8 (20)	1.34 [1.16-1.55]	<0.001
Sexuality			0.505
FSFI-6	13 (8)		
IIEF-5	12 (9)		
No sexual activity	43%	1	
Sexually active without sexual problems	26%	0.80 [0.32-2.02]	
Sexually active with sexual problems	32%	1.38 [0.62-3.04]	
SCS-SF	4.9 (0.9)	0.38 [0.25-0.58]	<0.001
HADS			
HADS total	9 (7)	1.18 [1.12-1.24]	<0.001
HADS depression	4 (4)	1.40 [1.26-1.55]	<0.001
HADS anxiety	5 (4)	1.26 [1.16-1.37]	<0.001

EORTC QLQ-C30/HN43 30-item core European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire/head and neck cancer, 43 items, *HADS* Hospital Anxiety and Depression Scale, *SCS-SF* Self Compassion Scale – Short Form

[a] Small: C02-laser of vocal fold, lip excision, ear amputation, skin excision small nose tumor. Moderate: excision of sublingual/submandibular salivary gland, transoral excision, lip surgery with reconstruction, partial sinus resection, skin excision with local reconstruction, neck surgery. Large: parotidectomy with neck surgery, marginal and segmental mandibular resection, transoral excision with reconstruction, extensive sinus surgery, maxillectomy, skin excision with neck surgery or reconstruction. Very large: commando procedure, laryngectomy, lateral temporal bone surgery

[b] n = 54 oropharyngeal cancer patients with a known HPV status

[c] OR per 10 point increase in subscale.

Supplementary Table S2. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Heleen C Melissant Anouk S Schuit
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Heleen C Melissant, MSc. PhD candidate Femke Jansen, PhD. Senior researcher Simone E.J. Eerenstein, PhD. MD. Pim Cuijpers, PhD. Professor. Ellen Laan, PhD. Professor. Birgit I Lissenberg-Witte, PhD. Senior researcher. Anouk S Schuit, MSc. PhD candidate. Kerry A. Sherman, PhD. Professor. C. René Leemans, PhD., MD. Professor. Irma M Verdonck-de Leeuw, PhD. Professor.
Occupation	3	What was their occupation at the time of the study?	PhD candidate, Senior researcher, Professor.
Gender	4	Was the researcher male or female?	First author: female
Experience and training	5	What experience or training did the researcher have?	The first author participated in a qualitative research interview training in the Netherlands in 2016. She conducted interviews and analysed qualitative data in 3 other studies that were published in international peer-reviewed scientific journals.
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	No
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Information about the research goal was included in the participant information letter and informed consent form. Participants were aware that the study was part of a PhD project.
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	See methods section
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	See methods section

Supplementary Table S2 continued.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	See methods section
Sample size	12	How many participants were in the study?	See results section
Non-participation	13	How many people refused to participate or dropped out? Reasons?	See results section
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	See methods section
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	See table 1. Patient characteristics
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	N/A
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	N/A
Field notes	20	Were field notes made during and/or after the interview or focus group?	N/A
Duration	21	What was the duration of the interviews or focus group?	N/A 79% of participants finished the total writing intervention between 15-60 minutes.
Data saturation	22	Was data saturation discussed?	N/A
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	2 coders
Description of the coding tree	25	Did authors provide a description of the coding tree?	See table 3: Qualitative results.
Derivation of themes	26	Were themes identified in advance or derived from the data?	See methods section: qualitative analysis
Software	27	What software, if applicable, was used to manage the data?	Atlas.ti 8
Participant checking	28	Did participants provide feedback on the findings?	No
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes - Quotations were presented. Quotations were not identified with a participant number.

Supplementary Table S2 continued.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes – See results section/Table 3
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes – See results section/Table 3
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Yes – See results section/Table 3

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357.

Chapter 4

The course of sexual interest and enjoyment in head and neck cancer patients treated with primary (chemo)radiotherapy

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ABSTRACT

Introduction

The aim of this prospective study was to investigate the course of sexual interest and enjoyment in relation to sociodemographic and clinical factors, health-related quality of life (HRQOL), and symptoms of psychological distress in head and neck cancer (HNC) patients treated with primary (chemo)radiotherapy.

Methods

HNC patients (n = 354) completed patient-reported outcome measures (PROMs) on HRQOL (EORTC QLQ-C30 and QLQ-H&N35, including the sexuality subscale covering less sexual interest and enjoyment), and psychological distress (HADS) pretreatment, at 6-week follow-up and at 3-, 6-, 12-, 18-, and 24-month follow-up (i.e., after treatment). Linear mixed models were used to analyse the course of sexuality from pretreatment to 24-month follow-up, and to investigate its relation to sociodemographic and clinical factors, HRQOL, and psychological distress as measured at baseline, and to investigate the course of sexuality from 6- to 24-month follow-up in relation to these factors measured at 6-month follow-up.

Results

Before start of treatment, 37% of patients reported having less sexuality, which increased to 60% at 6-week follow-up, and returned to baseline level from 12-month follow-up onwards. Older age ($p = 0.037$) and trouble with social contact ($p < 0.001$), weight loss ($p = 0.013$), and constipation ($p = 0.041$) before treatment were associated with less sexuality over time. Female gender ($p = 0.021$) and poor social functioning ($p < 0.001$) at 6-month follow-up were associated with less sexuality from 6- to 24-month follow-up.

Discussion

Less sexuality is often reported in HNC patients treated with (chemo)radiotherapy. Using PROMs in clinical practice may help identify patients who might benefit from supportive care targeting sexuality.

INTRODUCTION

Sexual issues are often reported in patients with cancer[1] and include changes in sexual function (e.g. decreased sexual desire and arousal, vaginal dryness, erectile and orgasm dysfunctions) and changes in sexual activity. Sexual issues can lead to significant distress and have a negative effect on well-being[2,3] and health-related quality of life (HRQOL)[4,5] of cancer patients. So far, most research on cancer and sexuality has been performed in patients with breast, prostate, or gynecological cancer, who, given the tumor site, are at high risk for developing sexual issues during and/or after treatment. However, head and neck cancer (HNC) patients are also at risk for developing sexual issues during and after cancer treatment, because they often have to deal with appearance changes in the (visible) head and neck area (e.g. facial scars due to surgery, skin problems due to (chemo)radiotherapy, or a stoma in the neck (in laryngectomized patients)), which can have a negative impact on body image and feelings of sexual attractiveness[6,7]. Moreover, functional barriers to sexuality may exist (e.g. problematic oral secretions, oral pain, or inability to move one's neck). A review showed that 24%-100% of HNC patients reported a negative effect on their sexuality, with higher rates reported in women and those without a partner[8]. Also, differences in sexuality have been found between subtypes of HNC. For example, at diagnosis, less sexual interest was reported as one of the worst three symptoms in HNC patients, except for patients with a cancer of the tonsil and nasopharynx[9]. In addition, a longitudinal study found that patients with oral or oropharyngeal cancer reported more issues with sexuality over time than patients with hypopharyngeal and laryngeal cancer[10].

More information is needed on HNC patients to investigate how often and when sexual issues arise and how it develops over time. Therefore, the first objective of this study was to investigate the course of sexual interest and enjoyment (hereafter referred to as "(less) sexuality") in HNC patients from pretreatment to 6-week and 3-, 6-, 12-, 18-, and 24-month follow-up (i.e. after treatment). Moreover, understanding who is at risk for developing less sexuality is important in order to adequately detect emerging sexual issues and timely referral to appropriate supportive care. Risk factors before treatment might differ from risk factors at 6-month follow-up, when the acute side effects of the (chemo)radiotherapy have disappeared. The second objective of this study was to examine whether sociodemographic and clinical variables, symptoms of anxiety and depression, and HRQOL, before start of treatment and at 6-month follow-up, are associated with less sexuality over time in HNC patients.

MATERIAL AND METHODS

Participants and procedure

Patients were included at the Department of Otolaryngology – Head and Neck Surgery and at the Department of Radiotherapy of the VU University Medical Center (VUmc), Amsterdam, The Netherlands. From January 2008 to June 2014, 525 newly diagnosed HNC patients were treated with primary (chemo)radiotherapy with curative intent. These patients were asked to fill out patient-reported outcome measures (PROMs) using OncoQuest[11-13], a touch screen computer-assisted data collection system which is part of standard clinical practice to enable monitoring of quality of life, or using paper and pencil. Patients were encouraged to complete the PROMs before start of treatment and at every follow-up visit at one of the two departments. Patients were included in this study when they (1) were treated with primary (chemo) radiotherapy with curative intent for cancer of the oral cavity, oropharynx, hypopharynx, or larynx; (2) completed the pretreatment sexuality items of the EORTC QLQ-H&N35; (3) were ≥18 years old; and (4) provided consent to use the collected PROMs for scientific research. According to the Dutch Medical Research Involving Human Subjects Act, ethical approval was not necessary, because patients were not subjected to procedures or required to follow rules of behavior.

Outcome measures

Patients filled out three PROMs: the EORTC QLQ-C30, EORTC QLQ-H&N35, and the Hospital Anxiety and Depression Scale (HADS). We assessed the PROMs before treatment and at 6 weeks, and 3-, 6-, 12-, 18-, and 24-month follow-up (i.e. after treatment).

The EORTC QLQ-C30 is a cancer-specific quality of life questionnaire. It contains a global QOL scale, five functional scales (physical, role, emotional, cognitive, and social), three symptom scales (fatigue, nausea/vomiting, and pain) and 6 single items (dyspnea, insomnia, loss of appetite, constipation, diarrhea, and financial difficulties). The EORTC QLQ-H&N35 is a module specifically designed for HNC patients[14]. It contains 7 symptom scales: oral pain (4 items), swallowing (5 items), senses (smell and taste) (2 items), speech (3 items), social eating (4 items), social contact (5 items), and sexuality (2 items). There are 11 single items covering problems with teeth, dry mouth, sticky saliva, cough, opening the mouth wide, feeling ill, weight loss or weight gain, use of nutritional supplements, feeding tubes, and use of painkillers. The primary outcome measure in this study was the EORTC QLQ-H&N35 “less sexuality” subscale, covering two questions: “During the last week have you felt less interest in sex?” and “During the last week have you felt less sexual enjoyment?”. The items were scored on a four-point Likert scale ranging from “not at all” (1) and “a little” (2) to “quite a bit” (3) and “very much” (4).

All scales and single items of the EORTC QLQ-C30 and EORTC QLQ-H&N35 are converted into a score from 0 to 100. For functioning scales and global QOL, a higher score indicates a better level of functioning, whereas for the symptom scales (including sexuality), a higher score represents higher levels of symptoms[14-16]. The EORTC QLQ-C30 and EORTC QLQ-H&N35 have shown good psychometric properties in patients with cancer[14,16]. There are cut-off scores available for the sexuality subscale (cut-off = 10)[17] as well as for other scales of the EORTC QLQ-C30 and H&N35[17,18].

The Hospital Anxiety and Depression Scale (HADS) is a 14-item scale measuring symptoms of anxiety and depression. This scale is proven to have adequate psychometrical properties to identify psychological distress in cancer patients[19-21]. A cut-off score of 14 for the total HADS and 7 for each of the anxiety and depression subscales was used[22,23].

Sociodemographic characteristics on age and gender were self-reported, and clinical characteristics were extracted from patients' medical files.

Statistical analyses

Descriptive statistics were generated for sociodemographic and clinical characteristics and outcome measures. Independent t-tests and Chi-square tests were used to examine potential differences in sociodemographic and clinical variables between included patients and non-participants.

To describe the longitudinal course of sexuality among HNC patients, linear mixed models were used with fixed effects for time and a random effect for subject. A Bonferroni correction was applied taking into account multiple testing (yielding a corrected $p = 0.01$ and 99% CI). To analyse potential factors associated with the course of sexuality over time, linear mixed models were used, with fixed effects for time, the potential factor(s), and time*factor, and a random effect for subject. A significant two-way interaction ($p < 0.05$) indicates that the course of sexuality over time differs between the different groups. A forward selection procedure (p-value for enter < 0.05) was performed to investigate which combination of factors predicted the course of sexuality best. Potential factors included age (dichotomized based on median split), gender (male/female), diagnosis (oral cavity, oropharynx, hypopharynx, larynx), adjuvant chemotherapy (yes/no), TNM stage (I to IV), the EORTC QLQ-C30 and EORTC QLQ-H&N35 subscales and individual items, as well as the HADS anxiety and depression subscale and total score. The EORTC QLQ-C30 and EORTC QLQ-H&N35 subscales and single items, and the HADS subscales and total score were dichotomized with evidence-based cutoff points[17,18,22,23]. If cut-off points were not available (for senses problems, trouble with social contact, teeth, opening mouth, dry mouth, coughing, feeling ill, pain killer use, nutritional supplement use, feeding tube, weight loss, and weight gain), dichotomization was based on the median split. We investigated potential factors associated with the course of sexuality over time before treatment as well as factors associated with the course of sexuality over time after treatment beginning at 6-month follow-up. The EORTC QLQ-C30, EORTC QLQ-H&N35, and HADS subscale scores and individual items were fixed at baseline for the first analysis and at 6 months for the second analysis. All analyses were performed according to the intention-to-treat principle. Patients treated for a recurrence, or second primary HNC tumor during follow-up, were excluded from that point of time onwards. Analyses were performed using the IBM Statistical package for the Social Sciences (SPSS) version 22 (IBM Corp., Armonk, NY USA). The significance level was set at 0.05.

RESULTS

Patient characteristics

Of 525 newly diagnosed HNC patients treated with primary (chemo) radiotherapy with curative intent, 12 patients were excluded because a tumor was localized in the nasopharynx, ear, or salivary gland or because of a lymph node metastasis from an unknown primary tumor. Of the 513 patients, 159 did not fill out any PROMs or the sexuality subscale items before start of treatment and were therefore excluded. In total, 354 patients were included in the study. There were no significant differences between the included patients and non-participants (Table 1). For 81% of the included patients at least one follow-up measurement was available, and response at follow-up measurements ranged between 22 and 56%.

Table 1. Patient characteristics.

Characteristic	**Included patients** *N* **= 354**	**Non-participants** *N* **= 159**	**p-value**
Mean age (SD)	61 (9)	62 (9)	0.17
Gender			0.16
Male	74%	68%	
Female	26%	32%	
Treatment			0.43
Radiotherapy	53%	49%	
Radiotherapy and chemotherapy	47%	51%	
Tumor site			0.42
Oral cavity	13%	12%	
Oropharynx	46%	39%	
Hypopharynx	12%	16%	
Larynx	31%	33%	
Tumor stage [a]			0.43
I	12%	9%	
II	15%	15%	
III	24%	20%	
IV	49%	56%	

Table 1 continued.

Characteristic	Included patients *N* = 354	Non-participants *N* = 159	p-value
Assessment moments [b]			
Before treatment	100%		
6-week follow-up	54%		
3-month follow-up	22%		
6-month follow-up	56%		
12-month follow-up	56%		
18-month follow-up	37%		
24-month follow-up	30%		

[a] Patients with an unknown TNM stage (non-participants n = 13; included patients n = 1) were excluded for this analysis. [b] Patients who died or had a metastasis or second primary tumor between assessments were detracted from the total.

Course of sexuality

Before start of treatment, 37% of HNC patients reported less sexuality, based on a cut-off score of 10[17] (mean = 17.1, SD = 26.4, range = 0–100), which increased to 60% at 6 week follow-up (mean = 34.7, SD = 35.3), and returned to baseline level over time with 37% at 12-month follow-up (mean = 16.7, SD = 24.9) and 24% at 24-month follow-up (mean = 13.2, SD = 27.8). In Figure 1, the means of the less sexuality subscale over time are presented. Results of the linear mixed models showed that from 12-month follow-up onwards, the difference in sexuality compared to the pretreatment score was no longer statistically significant (Table 2).

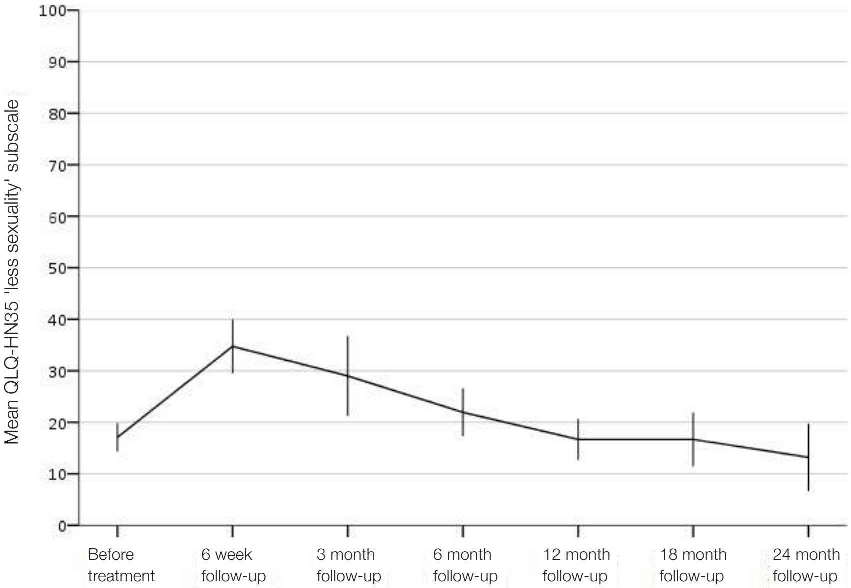


Figure 1. Course of sexuality in HNC patients before treatment, 6-week, and 3-, 6-, 12-, 18-, and 24-month follow-up. A higher score represents less sexual interest and enjoyment.

Table 2. Results of descriptives and linear mixed model analysis for the course of sexuality over time before treatment, 6-week, and 3-, 6-, 12-, 18-, and 24-month follow-up. A higher score represents less sexual interest and enjoyment.

	Descriptives	**Linear mixed model analysis**	
	Mean (SD)	**Mean change from pretreatment**	**99% CI**
Pretreatment (n = 354)	17.1 (26.4)	-	
6-week follow-up (n = 178)	34.7 (35.3)	17.3	12.0 to 22.6
3-month follow-up (n = 69)	29.0 (32.2)	13.9	6.1 to 21.7
6-month follow-up (n = 171)	21.9 (30.8)	5.4	0.04 to 10.8
12-month follow-up (n = 153)	16.7 (24.9)	2.3	-3.3 to 7.9
18-month follow-up (n = 92)	16.7 (25.3)	2.3	-4.5 to 9.2
24-month follow-up (n = 72)	13.2 (27.8)	-0.6	-7.7 to 7.6

Factors associated with the course of sexuality

Linear mixed model analyses showed that factors associated with the entire course of sexuality over time (pretreatment to 24-month follow-up) included the following: receiving chemotherapy, social functioning, appetite loss, constipation, diarrhea, trouble with social eating, trouble with social contact, trouble opening the mouth, dry mouth, and weight loss (Table 3).

Table 3. Results of the univariate linear mixed-model analyses regarding factors associated with the course of sexuality over time.

	Pretreatment to 24-month follow-up (n = 354)	**6- to 24-month follow-up (n = 171)**
	p-value	**p-value**
Demographic variables		
Time*Gender	0.163	0.099
Time*Age	0.056 [d]	0.192 [d]
Clinical variables		
Time*Diagnosis [a]	0.201	0.477
Time*Chemotherapy	**0.011**	0.956
Time*TNM stage	0.256	0.563
EORTC QLQ-C30		
Time*Global quality of life	0.121	0.093
Time*Physical functioning	0.066	**0.009** [c]
Time*Role functioning	0.493	**0.001** [c]
Time*Emotional functioning	0.095	0.210 [c]
Time*Cognitive functioning	0.091	**0.014** [c]
Time*Social functioning	**0.013** [b]	**<0.001**
Time*Fatigue	0.853	0.128 [c]
Time*Nausea and vomiting	0.076	**0.041**
Time*Pain	0.165	**0.002**
Time*Dyspnea	0.679	0.689
Time*Insomnia	0.266	0.994

Table 3 continued.

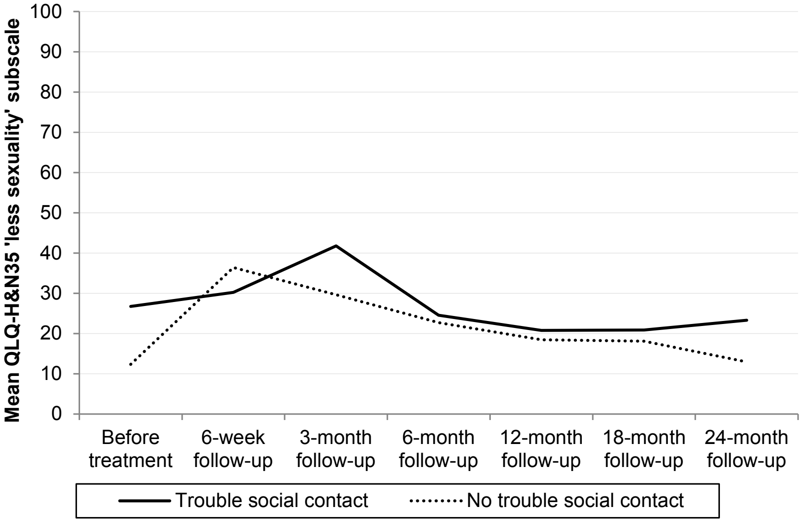
	Pretreatment to 24-month follow-up (n = 354)	**6- to 24-month follow-up (n = 171)**
	p-value	**p-value**
Time*Appetite loss	**0.019**	**0.005**
Time*Constipation	**0.030**	0.082
Time*Diarrhea	**0.047**	0.699
Time*Financial difficulties	0.322	**0.004**
EORTC-QLQ-H&N35		
Time*Oral pain	0.245	0.290 [c]
Time*Swallowing	0.188 [b]	**0.032**
Time*Senses problems	0.232	**0.009**
Time*Speech problems	0.451	0.348 [c]
Time*Trouble with social eating	**0.034**	**0.010**
Time*Trouble with social contact	**<0.001**	**0.014**
Time*Teeth	0.987 [b]	0.744
Time*Opening mouth	**0.018**	0.901
Time*Dry mouth	**0.026**	0.073
Time*Sticky saliva	0.653	0.208
Time*Coughing	0.151 [b]	0.993
Time*Felt ill	0.121	0.176
Time*Use of painkillers	0.377	0.054
Time*Nutritional supplements	0.144	**0.002**
Time*Feeding tube	0.656	**0.019**
Time*Weight loss	**0.001**	0.073
Time*Weight gain	0.063	0.353
HADS		
Time*HADS total	0.318 [b]	**0.012** [c]
Time*HADS depression	0.158 [b]	0.371 [c]
Time*HADS anxiety	0.639 [b]	0.113 [c]

Significant differences (p<0.05) are presented in bold font. [a] Patients with oropharynx cancer are selected as the reference group. [b] 1 missing value for social functioning, teeth and coughing; 2 missing values for swallowing; 22 missing values for HADS. [c] 1 missing value for physical-, role-, emotional- and cognitive functioning, oral pain, and speech problems; 2 missing values for fatigue; 16 missing values for HADS. [d] median split at pretreatment = 62 years; median split at 6-month follow-up = 61 years.

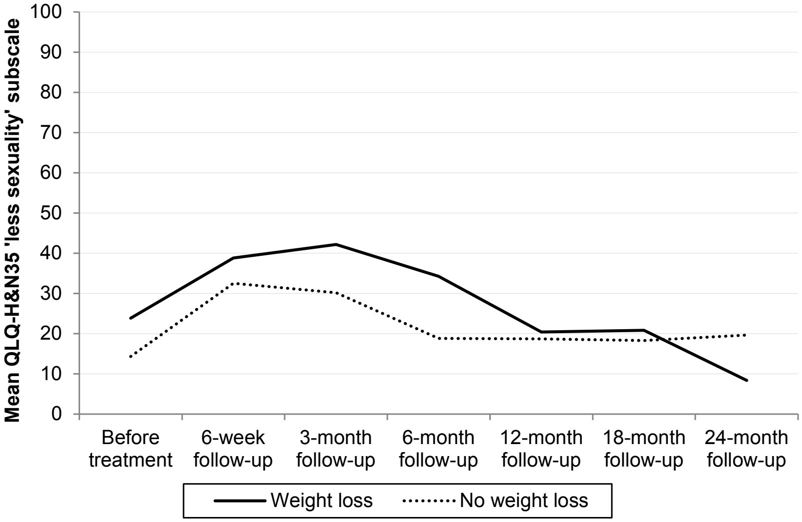
Factors associated with the post-treatment course of sexuality from 6- to 24-month follow-up were physical-, role-, cognitive-, and social functioning, nausea and vomiting, pain, appetite loss, financial difficulties, difficulty with swallowing, problems with senses, trouble with social eating, trouble with social contact, use of nutritional supplements, having a feeding tube, and psychological distress (HADS total).

The forward selection procedure revealed four factors measured prior to treatment that were associated with the course of sexuality over time (pretreatment to 24-month follow-up). First, HNC patients who reported trouble with social contact before treatment reported less sexuality than HNC patients who did not ($p < 0.001$), especially from 3-month follow-up onwards. Second, HNC patients who reported weight loss before treatment reported less sexuality than HNC patients without weight loss ($p = 0.013$); this difference declined over time. Third, HNC patients with constipation before treatment reported less sexuality than HNC patients without constipation ($p = 0.041$); this difference also declined over time. Fourth, HNC patients aged 62 years or older reported less sexuality than HNC patients younger than 62 years old ($p = 0.037$); this difference remained present over time. Graphical representations are shown in Figure 2 a-d.

a



b



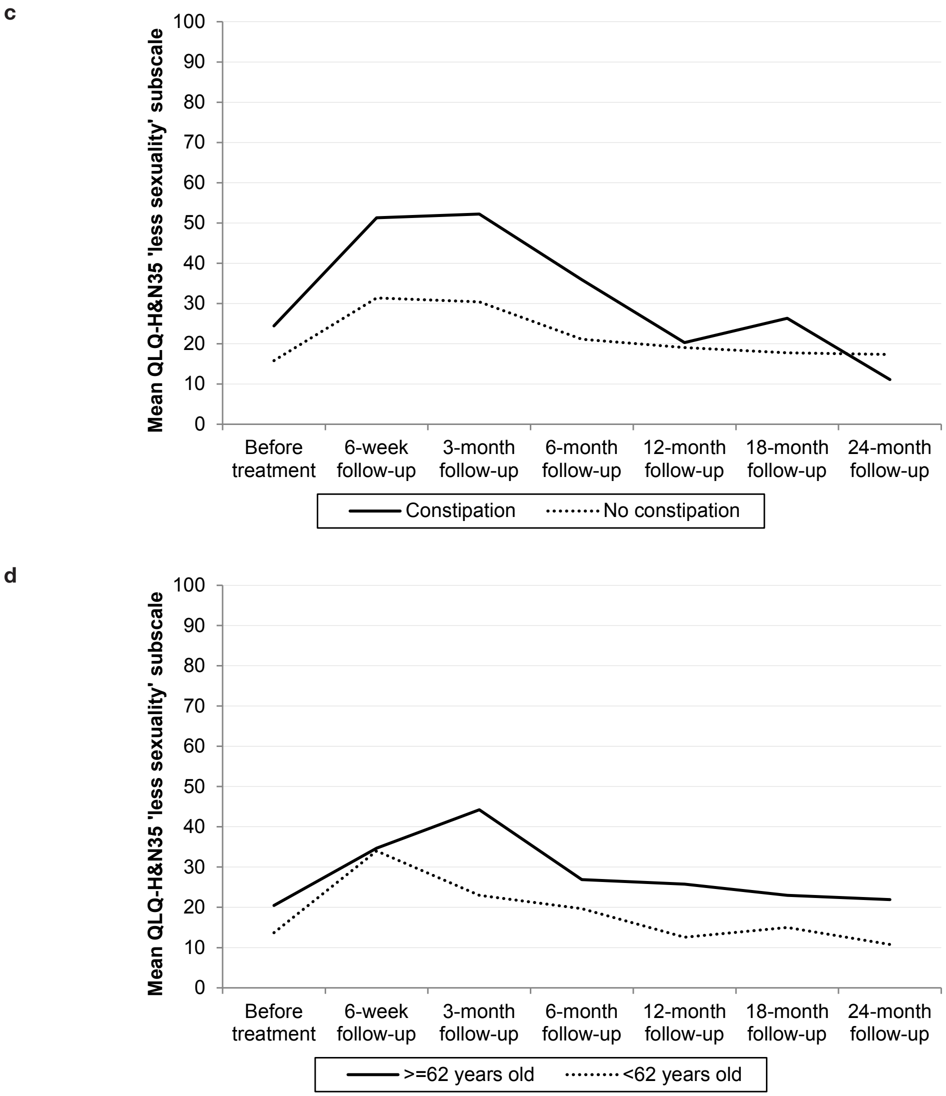


Figure 2 a-d. The course of sexuality before treatment, 6-week, and 3-, 6-, 12-, 18-, and 24-month follow-up, by the associated factor as measured before treatment. All other factors were set at their mean value. A higher score represents less sexual interest and enjoyment.

Two factors were associated with the post-treatment course of sexuality over time from 6- to 24-month follow-up. HNC patients reporting a low level of social functioning at 6-month follow-up reported less sexuality than patients who did not ($p < 0.001$); this difference declined over time (Figure 3a). Female HNC patients indicated experiencing less sexuality at 6-month follow-up than male HNC patients ($p = 0.021$). This difference reversed over time, showing that male HNC patients experienced less sexuality. In the long term, this difference between women and men disappeared (Figure 3b).

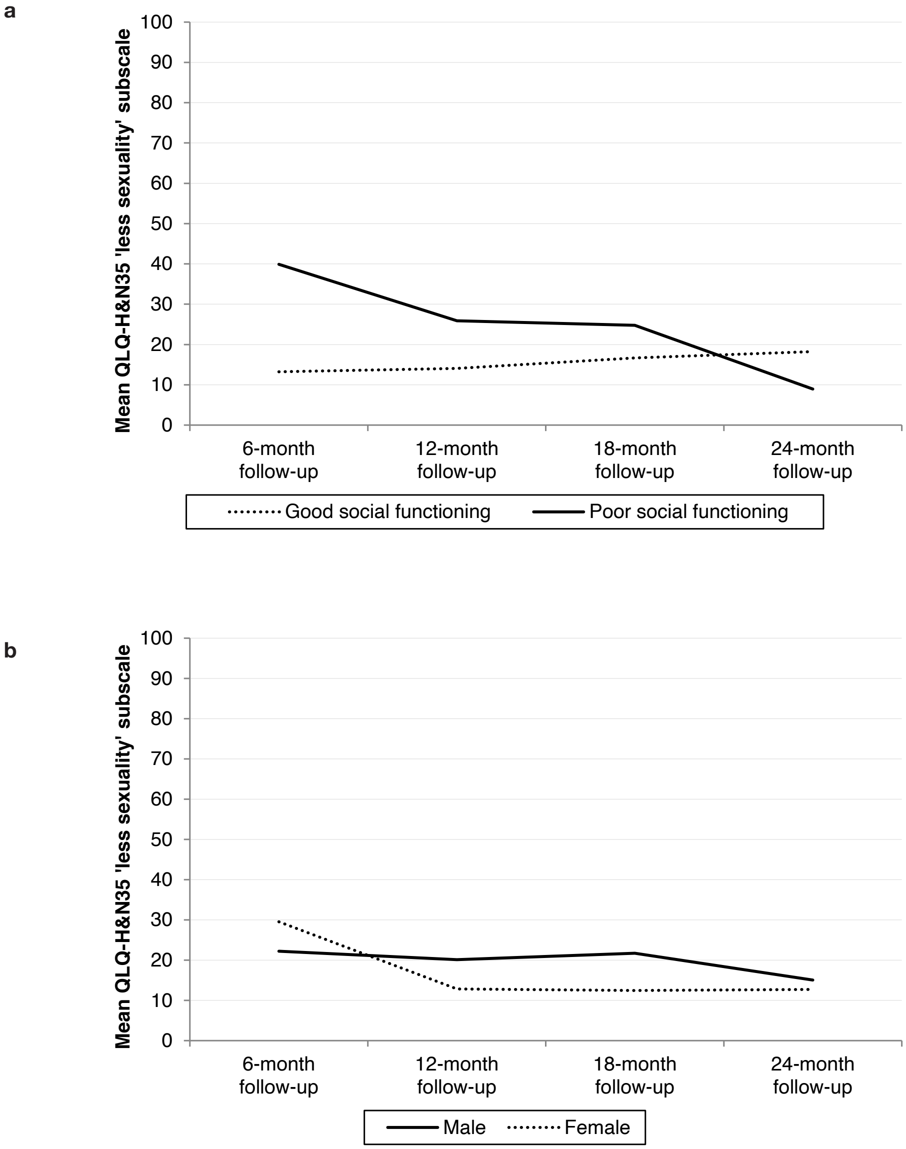


Figure 3 a-b. The course of sexuality at 6-, 12-, 18-, and 24-month follow-up, by the associated factor as measured at 6-month follow-up. All other factors were set at their mean value. A higher score represents less sexual interest and enjoyment.

DISCUSSION

In this study, we investigated the course of sexual interest and enjoyment over time and factors that were associated with it in HNC patients treated with primary (chemo)radiotherapy. Results showed that, prior to treatment, more than one-third of HNC patients reported less sexuality; 6 weeks after treatment, almost two-thirds reported less sexuality. In the long term, sexuality returned to baseline level. The peak in less sexuality 6 weeks after treatment might be explained by side effects resulting from the treatment, such as fatigue, feeling ill, nausea and vomiting, sticky saliva, and a dry mouth, which have previously been shown to peak at 6-week follow-up[10]. These symptoms may negatively impact sexual interest and enjoyment.

Three previous longitudinal studies among HNC patients[10,24,25] found higher scores of less sexuality prior to treatment[10,24] as well as at various follow-up times[10,24,25] An explanation may be that, in the current study, patients were treated with primary (chemo) radiotherapy, whereas in the previous studies, patients treated with surgery were also included[24,25], or all patients received adjuvant chemotherapy in addition to radiotherapy[10]. It is possible that surgical treatment leads to permanent facial disfigurement (e.g. scars or a tracheostomy) that may interfere with feelings of sexual attractiveness[7,26] and subsequently may lead to a higher score of less sexuality in the long term. Adjuvant chemotherapy in HNC is associated with symptoms (such as fatigue and adverse effects)[27-29] that might interfere with sexuality.

In the present study, we found that the course of sexuality over time in HNC patients during the first two years after diagnosis was associated with physical (weight loss, constipation), psychosocial (trouble with social contact, poor social functioning) as well as sociodemographic (age, gender) factors. Patients with weight loss and/or constipation reported less sexuality compared to patients without weight loss or without constipation. These problems are frequently reported consequences of HNC[30], as the tumor can cause pain and difficulty swallowing while eating. As a consequence, the poor nutritional status and low-fiber intake may induce constipation[31]. It is known that eating problems in cancer patients may lead to weakness, increased complications, and more side effects of the cancer treatment[32,33]. This might also explain why HNC patients who have constipation and weight loss at diagnosis report less sexuality over time.

Trouble with social contact and poor social functioning were also associated with less sexuality over time. This makes sense, given the fact that sex and intimacy generally involve social interaction with another person. In particular, the association with poor social functioning at 6-month follow-up is an interesting finding. The social functioning subscale explores interference with family life and social activities because of the physical condition or medical treatment[34]. It is possible that some HNC patients become more socially withdrawn, not only from family and friends but also from their partner, which can negatively impact their sexual life.

This study showed that female patients reported less sexuality than men as measured at 6-month follow-up. The literature reported mixed results regarding gender differences in sexuality in HNC patients[8,35-37]. It should be noted that the moderating effect of gender in this study was only reported 6 months after treatment and not prior to treatment. Moreover, the results reversed 12 months after treatment, where male HNC patients reported less sexuality. Results of this study also showed that older (> 62 years) HNC patients reported less sexuality over time than younger patients. This is in contrast to other studies that reported less sexuality in younger HNC patients[35,38]. Further qualitative and quantitative research is needed to gain further insight into age and gender differences regarding sexuality in HNC patients.

In this study, we found no significant association between sexuality and tumor subsite. This is in accordance with the study of Bjordal et al.[34] who also found no differences in sexuality among tumor subsites, as measured prior to the beginning of treatment. However, the results are in contrast with the study of Verdonck-de Leeuw et al.[10] who found less sexuality over time in patients with oral/oropharyngeal cancer compared to hypopharyngeal/laryngeal cancer. An explanation might be that, in our study, four different tumor groups were compared, in contrast to two tumor groups in the other study[10]. Future research should examine whether there are subsite-specific sexual symptoms. For example, surgically treated oral cancer may result in the loss of tongue and lip function and therefore may interfere with oral sex or kissing[35,39].

A strength of this study is the longitudinal design and large sample size (n = 354). A limitation of this study was that not all patients filled out the PROMS at every follow-up, which led to a fluctuating amount of data. However, participants did not differ from non-participants regarding sociodemographic and clinical characteristics. Linear mixed model analyses were used to handle the missing data at follow-up times, enabling usage of all collected data. Another limitation was that we used the sexuality subscale of the EORTC QLQ-H&N35, which contains only two items regarding sexual interest and sexual enjoyment. In order to gain a more comprehensive understanding of the impact of HNC on sexual well-being, a tool that specifically measures sexuality in HNC patients needs to be employed in future research. Furthermore, we did not have data on HPV status, which may be of importance in oral/oropharyngeal patients. However, a previous study did not find an association between sexual behavior and HPV status, although both patients with and without HPV showed significant decline in the frequency of sexual behavior at follow-up[40].

Conclusion

In conclusion, less sexuality is often reported in HNC patients treated with (chemo) radiotherapy. Less sexuality from pretreatment to 24-month follow-up is related to older age, pretreatment weight loss, constipation, and trouble with social contact. Less sexuality from 6- to 24-month follow-up is related to female gender and poor social functioning. Using PROMs in clinical practice may help identify those patients who might benefit from supportive care targeting sexuality.

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Chapter 5

Effect of stepped care on sexual interest and enjoyment in distressed head and neck cancer patients: a randomized controlled trial

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ABSTRACT

Introduction

A recent randomized controlled trial (RCT) in head and neck cancer (HNC) patients with psychological distress showed that a stepped care (SC) program targeting psychological distress compared to care as usual (CAU), is (cost)effective in reducing psychological distress.

Aim

The aim of the present study was to investigate whether SC can co-alleviate problems with sexuality. A secondary aim was to investigate whether the presence of an unmet sexual health need and having a psychiatric disorder (depression or anxiety) at baseline moderated any effect of SC on sexuality until one year follow-up.

Methods

HNC survivors (n = 134), randomized to SC or CAU, were assessed regarding their sexual interest and enjoyment before and after the intervention and at 3, 6, 9 and 12 months follow-up. Linear mixed models were used to evaluate differences in the course of sexual interest and enjoyment between SC and CAU.

Main Outcome Measure

The 'Sexuality' symptom subscale, part of the European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire, Head and Neck Cancer-specific module.

Results

Of all patients 76.1% had an unmet sexual need at baseline, 24.6% had a psychiatric disorder (anxiety or depression). SC did not reduce problems with sexual interest and enjoyment at any of the follow-up measurements compared to CAU (p = 0.85). This was neither moderated by an unmet sexual health need at baseline (p = 0.64) nor by the presence of a psychiatric disorder at baseline (p = 0.59).

Conclusion

A substantial number of HNC patients have unmet sexual health needs. SC targeting psychological distress does not reduce problems with sexuality in these patients. Interventions specifically targeting sexuality are recommended.

INTRODUCTION

Sexual problems are highly prevalent in cancer patients and include changes in sexual function, activity and pleasure (e.g., vaginal dryness, erectile and orgasm dysfunctions, decreased sexual desire, arousal and enjoyment)[1,2]. These problems can lead to significant distress and are, besides other adverse (bio)psychosocial consequences (e.g., pain, anxiety, fatigue), among the most negative influences of cancer and its treatment on quality of life[1-3]. Even though the cancer is located outside the sexual organs, head and neck cancer (HNC) patients are at risk for developing intimacy issues or sexual problems[4,5]. The disruption of physiological, psychological and social functioning that accompanies HNC could all negatively impact sexuality directly, indirectly and reciprocally[1,2]. For example, treatment of HNC patients often results in visible facial disfigurement (e.g., scars or stoma in the neck), communication complications and other psychological and functional deficits (e.g., problems with smell, speaking and swallowing) that may interfere with intimate contact or sexual performance (e.g., kissing or oral sex)[4-8]. Thus, sexuality of HNC patients may be affected in a multidimensional manner.

However, sexuality is often overlooked, despite being an integral part of general health[5,8,9]. Only a limited number of studies have investigated sexuality among HNC patients. These studies indicate that HNC and its treatment have a negative impact on sexuality, especially immediately after oncological treatment, and particularly in those patients with high levels of distress, disrupted social functioning, extensive disfigurement and advanced tumor stages[7,8,10,11]. Sexuality was listed in the top three of the most bothersome symptoms among HNC patients[12]. Furthermore, over one-fifth of HNC patients who underwent a total laryngectomy expressed that their need for supportive care targeting sexual problems was not satisfactorily met[13]. These findings indicate that adequate screening and interventions are needed to help detect and address intimacy issues and sexual problems in HNC patients.

Recently, a randomized controlled trial (RCT) was conducted to investigate efficacy of stepped care (SC) directed at psychological distress compared to care as usual (CAU) in HNC and lung cancer (LC) patients with psychological distress[14,15]. The findings showed that SC significantly reduced psychological distress and improved quality of life, particularly in patients with a psychiatric disorder.

Poor functioning in the general life domain (e.g., low self-esteem, depression and neuroticism) may negatively affect the marital and sexual domain in cancer patients[11,16,17]. Given the significant association between psychological distress and sexual problems[8,11,16,17], it is important to understand how these co-existing symptoms can be alleviated. Therapeutic interventions targeting sexuality can improve psychological wellbeing[18], but it is still unknown whether interventions targeting psychological distress also reduce sexual problems in cancer patients.

Although SC was not specifically directed at sexual problems, it is plausible that sexual interest and enjoyment may also improve, given that psychological distress decreased due to SC. The purpose of the current (post-hoc) study was, therefore, to explore the effect of SC compared to CAU on the course of sexual interest and enjoyment, using data from the above mentioned RCT. Another purpose was to examine whether the effect of SC was moderated by having an unmet sexual health need and by the presence of a psychiatric disorder at baseline. It was hypothesized that SC targeting psychological distress also reduces problems with sexual interest and enjoyment among HNC patients.

MATERIAL AND METHODS

Study design and population

In this study, analyses were performed using data of a parallel-group RCT on the efficacy of SC among HNC and LC patients with psychological distress[15]. HNC patients and LC patients who visited the outpatient clinic of the Amsterdam University Medical Centers (Amsterdam UMC), location VU University medical center (VUmc), between 2009 and 2013 for a follow-up consultation at least one month after curative treatment were randomly allocated (1:1) by an independent person to SC or CAU. Eligible patients had psychological distress (a Hospital Anxiety and Depression Scale (HADS)[19] distress score >14, or a HADS anxiety or depression score > 7. The SC program consisted of four steps: (1) watchful waiting, (2) guided self-help via Internet or a booklet, (3) face-to-face problem-solving therapy, and (4) specialized psychological interventions and/or psychotropic medication. The four steps focused on psychological distress and not specifically on sexuality. Patients who did not recover after a SC-treatment step (HADS anxiety or depression score remained above 7) proceeded to the next step in the SC program. A detailed description of the study design and SC program can be found elsewhere[14,15]. Informed consent was obtained prior to any data collection. The study was approved by the Medical Ethics Committee of Amsterdam UMC, location VUmc, was registered in the Netherlands Trial Registration (NL1758)[14] and conducted according to the principles of the Declaration of Helsinki. More information on the eligibility criteria, randomization procedure and sample size calculation can be found in previous publications[14,15].

Data

All patient-reported outcome measures (PROMs) were collected at baseline (T0), after the SC-intervention period (time depended upon duration of the SC program) or control period

(4 months) (T1), and 3, 6, 9, and 12 months after T1, using paper and pencil or OncoQuest, a touch screen computer-assisted data collection system[20,21]. On average, time between T0 and T1 was comparable[15].

Primary outcome

The patient-reported outcome measure was the ‘Sexuality’ symptom subscale, part of the European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire, HNC-specific module (EORTC QLQ-H&N35)[22-24]. This subscale contains two questions on sexual interest and enjoyment: “During the last week have you felt less interest in sex?” and, “During the last week have you felt less sexual enjoyment?”. Both items are scored on a four-point scale (“not at all”, “a little”, “quite a bit”, “very much”). The scores of these two items are averaged and then transformed into a scale ranging from 0-100, with higher scores implying less sexual interest and enjoyment. A score higher than 10 on this subscale indicates an unmet need for help in this domain (cut-off = 10)[24].

Other outcomes

Sociodemographic and clinical variables

Information on age (continuous), gender (male, female), marital status (married/living together, unmarried/divorced/widow), years of education (continuous) and employment status (paid job, no paid job) was collected by means of self-report questionnaires. Information about tumor location (lip/oral cavity/oropharynx, hypopharynx/larynx, other), tumor stage (I, II, III, IV), and type of treatment (surgery, radiotherapy, chemoradiation, surgery + radiotherapy, surgery + chemoradiation, surgery + chemotherapy) was obtained from medical records.

Psychological distress

The HADS is a 14-item psychometrically sound, self-assessment scale for measuring distress (total HADS score) with two subscales, anxiety (HADS-A) and depression (HADS-D), developed for non-psychiatric patients. The total HADS score ranges from 0 to 42, the subscales from 0 to 21, where higher scores represent more distress[19,25]. HADS at baseline was assessed by telephone or by means of OncoQuest[20,21]. The presence of a psychiatric (depressive or anxiety) disorder was assessed by telephone using the Composite International Diagnostic Interview (CIDI)[26], a comprehensive, structured interview designed for the assessment of mental disorders such as anxiety and depression by trained lay interviewers.

Health-related quality of life (HRQOL)

A global quality of life (QOL) scale and five functional scales (physical, role, emotional, cognitive and social) were assessed with the EORTC Quality of Life Questionnaire Core 30 questions (EORTC QLQ-C30); a cancer specific questionnaire. All scales and single items were linearly transformed into a score from 0 to 100, with a higher score indicating a higher level of functioning. The questionnaire has shown good psychometric properties in cancer patient populations[23,27].

Statistical analyses

All analyses were performed using SPSS version 20 (IBM Corp., Armonk, NY). Sociodemographics, clinical characteristics, HADS scores, CIDI diagnosis, and QOL measurements of the study sample (at baseline) were summarized using descriptive statistics. Independent samples t-tests and χ2 tests were used to examine whether randomization of the HNC patients had resulted in a balanced distribution of sociodemographic and clinical characteristics, global QOL and all functioning domains across SC and CAU. Independent samples t-tests were also used to measure differences between SC and CAU in sexual interest and enjoyment at each time-point. An absolute difference in sexual interest and enjoyment ≥ 10% of the instrument range was considered clinically meaningful[28]. A linear mixed model (LMM) was used to compare differences in the course of sexual interest and enjoyment between SC and CAU, with fixed effects for intervention, time-point and their two-way interaction, and a random intercept for subject. To control for a potential confounding effect of differences in sexual interest and enjoyment at baseline between the two interventions, an adjusted LMM was used where sexual interest and enjoyment at baseline was added as a fixed covariate to the previous model. Additionally, two other adjusted LMM's were used to investigate the effect of SC on the course of sexual interest and enjoyment with two potential moderators: a psychiatric disorder at baseline (based on the CIDI) and having an unmet sexual health need at baseline (sexuality score > 10[24], using a random intercept for subjects, fixed effects for intervention, time-point, moderator, and all two-way and three-way interactions. For all analyses missing data were excluded analysis-by-analysis rather than listwise and a p-value of < 0.05 was considered statistically significant. The data were analyzed on an intention-to-treat basis.

RESULTS

Sample characteristics

Sexuality data were unavailable for all 9 LC patients (Figure 1). Of the remaining 147 HNC patients, 134 patients (67 in the SC and 67 in the CAU group) provided a baseline score (T0) on the sexuality subscale. Patients in the SC group scored significantly better on sexual interest and enjoyment at baseline (T0): 39.5 versus 51.7; p = 0.040. They also scored significantly better on the HADS-total, HADS-D and the EORTC QLQ-C30 social functioning subscale, see Table 1.

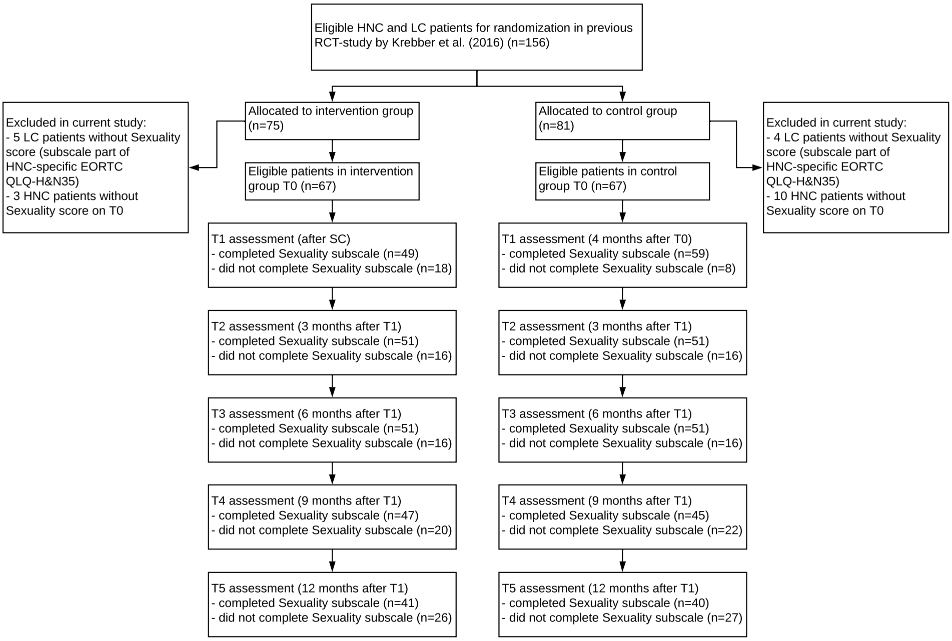

Figure 1. CONSORT flow diagram.

Table 1. Patient characteristics at baseline.

	Intervention (n = 67)	**Control (n = 67)**	**Total (n = 134)**	**p-value**
Age (mean, SD)	62.5 (8.5)	61.1 (9.9)	61.8 (9.2)	0.37
Gender				0.86
Male	44 (65.7%)	42 (62.7%)	86 (64.2%)	
Female	23 (34.3%)	25 (37.3%)	48 (35.8%)	
Paid job				0.86
Yes	22 (32.8%)	24 (35.8%)	46 (34.3%)	
No	45 (67.2%)	43 (64.2%)	88 (65.7%)	
Marital status				0.57
Married/living together	49 (73.1%)	45 (67.2%)	94 (70.1%)	
Unmarried/divorced/widowed	18 (26.9%)	22 (32.8%)	40 (29.9%)	
Years of education				0.29
5-10	33 (49.3%)	24 (35.8%)	57 (42.5%)	
11-16	30 (44.7%)	38 (56.7%)	68 (50.8%)	
17-21	4 (6.0%)	5 (7.5%)	9 (6.7%)	
Tumor location				0.079
Lip/oral cavity/oropharynx	29 (43.3%)	42 (62.7%)	71 (53%)	
Hypopharynx/larynx	21 (31.3%)	14 (20.9%)	35 (26.1%)	
Other head and neck cancers	17 (25.4%)	11 (16.4%)	28 (20.9%)	

Table 1 continued.

	Intervention (n = 67)	Control (n = 67)	Total (n = 134)	p-value
Tumor stage				0.22
Unknown	7 (10.4%)	2 (3.0%)	9 (6.7%)	
I	13 (19.4%)	17 (25.4%)	30 (22.4%)	
II	15 (22.4%)	9 (13.4%)	24 (17.9%)	
III	9 (13.4%)	13 (19.4%)	22 (16.4%)	
IV	23 (43.3%)	26 (38.8%)	49 (36.6%)	
Tumor treatment				**0.005**
Surgery	11 (16.4%)	19 (28.4%)	30 (22.4%)	
Radiotherapy	22 (32.8%)	12 (17.9%)	34 (25.4%)	
Chemoradiation	5 (7.5%)	18 (26.9%)	23 (17.2%)	
Surgery + radiotherapy	25 (37.3%)	14 (20.9%)	39 (29.1%)	
Surgery + chemoradiation	4 (6.0%)	3 (4.4%)	7 (5.2%)	
Surgery + chemotherapy	0	1 (1.5%)	1 (0.7%)	
Time since treatment				0.65
< 7 months	26 (38.8%)	23 (34.3%)	49 (36.6%)	
7-12 months	10 (14.9%)	14 (20.9%)	24 (17.9%)	
> 12 months	31 (46.3%)	30 (44.8%)	61 (45.5%)	
Anxiety or depression disorder (CIDI)				0.42
Yes	14 (20.9%)	19 (28.4%)	33 (24.6%)	
No	53 (79.1%)	48 (71.6%)	101 (75.4%)	
HADS (mean, SD)				
Total	17.5 (5.2)	19.5 (5.8)	18.5 (5.6)	**0.030**
Depression	8.28 (3.6)	9.96 (3.7)	9.62 (3.6)	**0.009**
Anxiety	9.18 (3.6)	9.58 (3.7)	9.38 (3.7)	0.53
EORTC QLQ-C30 (mean, SD)				
Global quality of life	59.5 (19.8)	55.5 (19.5)	57.46 (19.7)	0.24
Physical functioning	71.6 (20.9)	70.7 (20.8)	71.16 (20.8)	0.79
Role functioning	62.2 (26.7)	55.5 (26.0)	58.83 (26.5)	0.14
Emotional functioning	58.3 (26.1)	56.3 (22.6)	57.30 (24.3)	0.65
Cognitive functioning	71.4 (27.3)	70.6 (24.5)	71.02 (25.9)	0.87
Social functioning	71.9 (25.2)	58.7 (27.1)	65.30 (26.9)	**0.004**
EORTC QLQ-H&N35 (mean, SD)				
Sexuality subscale	39.6 (34.6)	51.7 (33.6)	45.65 (34.5)	**0.040**
Unmet sexual health need (sexuality subscale > 10)				0.068
Yes	46 (68.7%)	56 (83.6%)	102 (76.1%)	
No	21 (31.3%)	11 (16.4%)	32 (23.9%)	

Significant differences ($p < 0.05$) are presented in bold font.

SD standard deviation, *CIDI* Composite International Diagnostic Interview, *HADS* Hospital Anxiety and Depression Scale, *EORTC QLQ-C30* European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, *H&N35* Head and Neck specific module.

Effect of SC on sexual interest and enjoyment post-intervention

When comparing differences in sexual interest and enjoyment between SC and CAU per time-point, patients in the SC group scored statistically and clinically better post-intervention (T1) (34.7 versus 54.2; p = 0.004). However, when correcting for the baseline difference in sexual interest and enjoyment, no significant within-subjects change from baseline (T0) to post-intervention (T1) was found (p = 0.37).

Effect of SC on the course of sexual interest and enjoyment

LMM corrected for the between-group baseline difference in sexual interest and enjoyment showed that the course of sexual interest and enjoyment over time-points did not differ between SC and CAU groups (time-point * intervention: p = 0.85), see Figure 2. Of the patients, 76.1% had an unmet sexual need at baseline, and 24.6% had a psychiatric disorder, see Table 1. Neither having a psychiatric disorder at baseline (time-point * intervention * psychiatric disorder: p = 0.59) nor an unmet sexual health need at baseline (time-point * intervention * sexuality: p = 0.64) moderated the effect of SC on the course of sexual interest and enjoyment.

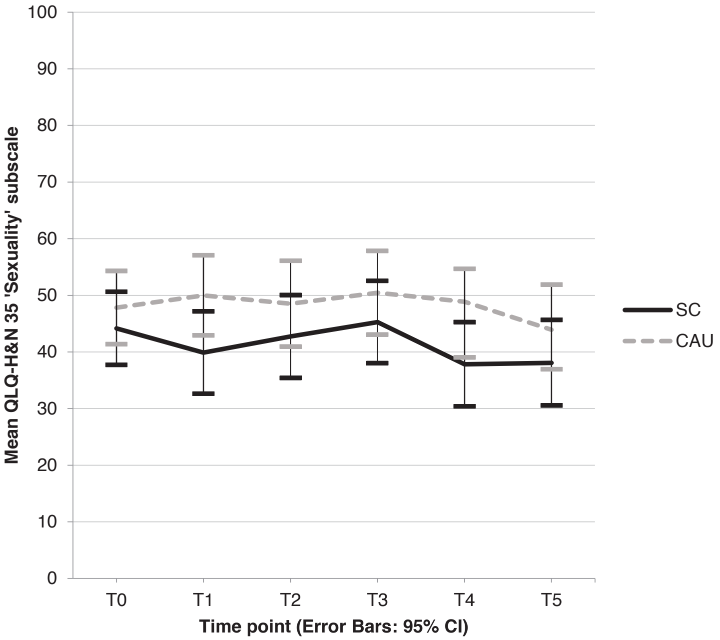

Figure 2. Effect of SC (Stepped Care) and CAU (Care As Usual) on sexual interest and enjoyment from T0 (pre-intervention) to T5 (12 months follow-up), corrected for between-group baseline differences, with 95% confidence intervals. Higher scores represent less sexual interest and enjoyment.

DISCUSSION

A substantial number of HNC patients were found to have an unmet sexual health need. SC did not reduce problems with sexual interest and enjoyment at any of the follow-up measurements compared to CAU, after correcting for baseline differences. Also, moderator analyses showed that patients with an unmet sexual health need at baseline and patients with a psychiatric disorder at baseline had no greater benefit from SC. These findings suggest that mere alleviation of illness-related psychological distress through SC is insufficient to effectively improve sexual interest and enjoyment in HNC patients, implying that interventions specifically targeting sexuality are needed for (HNC) patients who experience sexual problems.

The latter suggestion is supported by a study of Hummel et al.[29] that demonstrated that internet-based cognitive behavioral therapy directed at sexual functioning in breast cancer survivors with sexual dysfunction significantly reduced sexual problems and body image concerns. Online therapy was guided by a psychologist and specifically tailored to the sexual problems of each patient. Another study evaluated a telephone counseling intervention to improve psychosocial outcomes including sexual dysfunction in early stage breast cancer patients. Sexual functioning only improved in the intervention group, where sexual functioning was deliberately targeted[30]. The active control group (without sexual counseling) showed no improvement in sexual functioning.

Considering these findings, it can be concluded that interventions targeting psychological distress do not co-alleviate sexual problems in cancer patients. Interventions directed at sexuality address both psychological and sexual issues and possibly also their interaction. Thus, an integral approach – specifically targeting psychological and sexual issues together - is recommended for mental health care in cancer patients.

Strengths of this study are the randomized controlled design, the long follow-up period, inclusion of an active control group, and use of LMM which enables use of all collected data. A major limitation was that sexuality was assessed with two items only, since the RCT from which the data were adopted did not specifically focus on sexuality[15]. Validity of these items and sensitivity to change may be limited.

Future research may incorporate a more comprehensive and valid measure of sexual function (assessing problems as well as wellbeing) in interventions for (HNC) cancer patients and their partners. Such a sexual health questionnaire is currently being developed according EORTC guidelines[31,32]. When the psychometric qualities of this measure are established, it can be used to evaluate interventions or to tailor and monitor care. Given the substantial unmet sexual health need and the importance of sexuality to general health, HNC patients and their partners should be asked whether they experience sexual problems and want referral for help[33-35].

Conclusion

A substantial number of HNC patients have unmet sexual health needs. SC targeting psychological distress does not reduce problems with sexual interest and enjoyment in these patients. Interventions specifically targeting sexuality are needed for patients who experience sexual problems.

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Chapter 6

A structured expressive writing activity targeting body image distress among head and neck cancer patients: who do we reach and what are the effects?

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ABSTRACT

Introduction

Disfigurement and dysfunction following head and neck cancer (HNC) treatment can induce body image distress. The aim of this pilot study was to investigate the reach and effects of My Changed Body (MyCB), an expressive writing activity based on self-compassion, among HNC patients.

Patients and methods

This pilot study had a pretest-posttest design. HNC patients received an invitation to complete a baseline survey on body image distress. At the end of the survey, patients were asked if they were interested in the intervention study. This entailed the writing activity and a survey one week and one month post-intervention. The reach was calculated as the percentage of patients who participated in the intervention study, among (1) all eligible patients and (2) those who filled in the baseline survey only. Linear mixed models were used to analyse the effect on body image distress. Logistic regression analysis was used to investigate factors associated with the reach and reduced body image distress. MyCB was evaluated using study-specific questions.

Results

The reach of MyCB was 15-33% and was associated with lower education level, more social eating problems and fewer wound healing problems. Among 87 participants, 9 (10%) showed a clinically relevant improvement in body image distress. No significant effect on body image distress was found. Self-compassion improved significantly during follow-up until one month post-intervention ($p = 0.003$). Users rated satisfaction with MyCB as 7.2/10.

Discussion

MyCB does not significantly improve body image distress, but is likely to increase self-compassion, which sustains for at least one month.

INTRODUCTION

Head and neck cancer (HNC) patients have a high risk of body image distress, since they often have to deal with body changes that cannot be easily hidden. Surgical treatment may lead to scars, disfigurements, an affected facial contour and expression, and for some, living with a tracheostomy[1,2]. Radiotherapy may result in fibrosis[3]. Surgery and radiotherapy may also induce lymphedema in the head and neck region[4]. Moreover, functional problems may occur that can negatively influence body image, such as speech problems or difficulties with eating[5]. A changed face can have profound personal and social consequences, affecting one's identity and social life[1,6,7]. Sexual concerns may also be present, for example, because patients have a diminished feeling of sexual attractiveness[2]. It is estimated that 13-20% of HNC patients develop body image distress because of their changed body[8]. Body image is defined as "thoughts, feelings and perceptions about the entire body and its functioning"[9]. HNC patients with body image distress have a decreased health-related quality of life (HRQOL) and increased symptoms of depression[10,11].

To reduce body image distress, an intervention called "My Changed Body" (MyCB) was developed and tested among breast cancer patients[12]. MyCB is an online writing activity that makes use of two elements: self-compassion and expressive writing. Self-compassion involves practicing common humanity, mindful awareness and expressing self-kindness when suffering[13]. Stimulating self-compassion might improve people's body image[14], especially in painful situations that are related to feelings of loss or rejection[13,15], and provides a buffer against negative thoughts and feelings about the body[16]. Research among cancer survivors has shown that self-compassion is inversely related to both body image distress and psychological distress[17], and it may mediate the association between body image distress and psychological distress[18]. The other element in MyCB, is guided expressive writing with a self-compassion focus. This entails asking individuals to choose a traumatic or upsetting experience and to write about their deepest thoughts and feelings[19]. Expressive writing may improve physical and psychological health outcomes[20,21]. A randomized controlled trial (RCT) among 306 breast cancer patients demonstrated that MyCB was significantly more effective in reducing body image distress and psychological distress, and in improving self-compassion, compared to unstructured expressive writing[22].

The main objective of this study is to investigate the reach and effects of MyCB among HNC patients. It is hypothesized that we will reach 13-24% of HNC patients[10,23,24], and that MyCB will reduce body image distress, compared to pre-intervention levels. Possible factors associated with the reach are explored: sociodemographic and clinical characteristics, body image distress, body appreciation, self-compassion, psychological distress, HRQOL, HNC symptoms and sexuality. Furthermore, possible associations between reduced body image distress post-intervention and sociodemographic and clinical characteristics are investigated.

METHODS

Participants and procedures

Between September 2018 and September 2019, eligible HNC patients from the Department of Otolaryngology – Head and Neck Surgery at Amsterdam UMC, location VUmc, were recruited to participate in this study. The local ethics committee of VU University Medical Center decided that, according to the Dutch Medical Research Involving Human Subjects Act, ethical approval was not necessary as patients were not subjected to procedures or required to follow rules of behavior. All participants signed informed consent.

HNC patients were eligible if they: (1) received treatment for HNC with curative intent; (2) completed treatment 6 weeks to 5 years prior; (3) provided written informed consent. Exclusion criteria were: <18 years old, cognitive impairments, inability to read and write Dutch, and participation in a prospective cohort study among HNC patients[25].

This non-randomized pilot study consists of two parts. The first part is a cross-sectional survey on body image distress. Eligible HNC patients received an invitation letter from their physician to complete this paper-based survey (T0). The second part is a pretest-posttest study. At the end of the T0 survey, patients were asked if they were interested in an intervention study to reduce body image distress. Interested patients received information on the study and MyCB, and signed a second informed consent form. Next, the researcher provided HNC patients access to MyCB by sending the booklet or providing website login instructions, based on preference. Patients also completed a paper-based survey one week (T1) and one month (T2) post-intervention.

Intervention “My Changed Body”

MyCB was developed and researched in Australia targeting breast cancer patients[12]. In this study, MyCB (in Dutch “Koester je lijf”) was adapted and translated for use by Dutch HNC patients. A forward-backward translation procedure was followed, and texts were revised by a researcher specialized in writing interventions after cancer. Next, MyCB was tested for usability amongst 4 HNC patients and their feedback was incorporated. MyCB was made available as a booklet and via a website. MyCB is a self-paced writing intervention that takes approximately 30 minutes to complete. Patients are initially asked to write freely introducing a negative event related to their changed body after HNC treatment, exploring their deepest thoughts and emotions. Patients then continue writing, guided by written prompts designed to enhance self-compassion toward themselves and their post-cancer body[13].

Outcome measures

Reach of MyCB

The reach of MyCB was calculated by dividing the number of HNC patients who participated in the intervention study on MyCB, by the total number of (1) eligible HNC patients for the baseline survey; and (2) all HNC patients who filled in the baseline survey (including those who did not participate in the intervention study).

Effects of MyCB

The primary outcome was body image distress. The 10-item Body Image Scale (BIS)[26] measures affective, behavioral and cognitive body image symptoms and was developed for use in cancer populations. Items can be answered on a 4-point Likert scale ranging from 0 “not at all” to 3 “very much”. A total score (range 0-30) is calculated by summing up the items: a higher score indicates a higher level of body image distress. The BIS has shown adequate psychometric properties[27] and is translated and validated in Dutch[28].

Secondary outcomes included body appreciation, self-compassion, psychological distress, HRQOL, HNC symptoms “social contact” and “wound healing” (significantly associated with body image distress in a previous study[8]), and sexuality. Body appreciation was measured with the Body Appreciation Scale (BAS-2)[29]. Self-compassion was assessed with the Self-Compassion Scale–Short Form (SCS-SF)[30]. Psychological distress was measured using the Hospital Anxiety and Depression Scale (HADS), and contains two subscales: anxiety (HADS-A) and depression (HADS-D)[31]. HRQOL was assessed with the EORTC QLQ-C30 (summary score)[32,33]. The EORTC QLQ-HN43 is a module specifically designed for HNC patients[34] and was used to measure HNC symptoms. Sexuality was assessed with the 6-item Female Sexual Function Index (FSFI-6)[35] for women and with the 5-item International Index of Erectile Function (IIEF-5)[36] for men. Patients were categorized in the “no sexual activity” group if they reported not to have had sexual activity and intercourse in the past 4 weeks. Validated cut-off scores[35,36] were used to characterize patients either as having reported sexual problems or not, to enable cross-gender analyses. Sexuality was not measured at T1, because the FSFI-6 and IIEF-5 assess symptoms from last 4 weeks. All other instruments were measured at T0, T1 and T2. All above-mentioned instruments are validated and translated in Dutch[34,37-42].

Factors associated with the reach and with reduced body image distress

We investigated factors associated with the reach and with reduced body image distress in terms of sociodemographic and clinical characteristics. Sociodemographic items were included in T0. Clinical characteristics were retrieved from medical files. Furthermore, T0 scores for body image distress, body appreciation, self-compassion, psychological distress, HRQOL, HNC symptoms and sexuality were analysed as potential factors associated with the reach.

Evaluation of MyCB

In total, 11 study-specific questions in T1 assessed how HNC patients evaluated MyCB (Table 3).

Statistical analyses

The reach and MyCB evaluation questions were explored using descriptive statistics. To investigate factors associated with the reach, MyCB participants were compared to non-participants (Supplementary Table S1). Univariate logistic regression and multiple logistic regression with a stepwise forward selection procedure was applied. Variables were added one by one to the multiple regression model, with p-value for entry <0.05.

Linear mixed models were used to test the effect of MyCB on the BIS and secondary outcomes. Models included a fixed effect of time and a random intercept for participants. Data were analysed according to the intention-to-treat principle and all participants were approached for T1 and T2. We performed a sensitivity analysis among patients who made use of MyCB. Usage was defined as having at least answered the first prompt and one self-compassion prompt. To assess changes between T0 and T2 in sexual activity and reported sexual problems, McNemar tests were performed.

To identify possible differences in the course of body image distress over time between HNC patients with a BIS score ≥ 8 and those with a BIS score < 8 at baseline, linear mixed models were used, with fixed effects for time, the dichotomized BIS score and their two-way interaction, and a random effect for subject. A significant two-way interaction (p-value < 0.05) indicates that the change in outcome over time differs between the two groups. A cut-off score of 8 was used, consistent with prior research[43].

To investigate factors associated with reduced body image distress, univariate logistic regression analysis was applied. HNC patients who had a clinically relevant reduction of at least 3 points on the BIS between T0 and T2 (10% of the instrument range[44]), were compared to those without a 3-point reduction.

All analyses used the standard alpha level of 0.05 and were carried out using SPSS version 26 (IBM Corp., Armonk, NY).

Sample size calculation

To show a reduction of 3 points[22] on the total BIS between T0 and T2, in total 84 HNC patients were needed for the intervention study (based on a power of 80% and a significance level of 5%). In this calculation we anticipated a 20% dropout rate, based on prior experience[45,46].

RESULTS

Study sample

In total, 521 HNC patients were invited for a survey on the prevalence of body image distress[8], of whom 233 participated (Figure 1). Of these 233 patients, 76 agreed to participate in the intervention study. To achieve the necessary 84 participants, another 39 HNC patients were directly invited for the MyCB intervention study (and excluded from the reach analysis) of which 11 participated, resulting in a total of 87 patients. Patient characteristics are shown in Table 1.

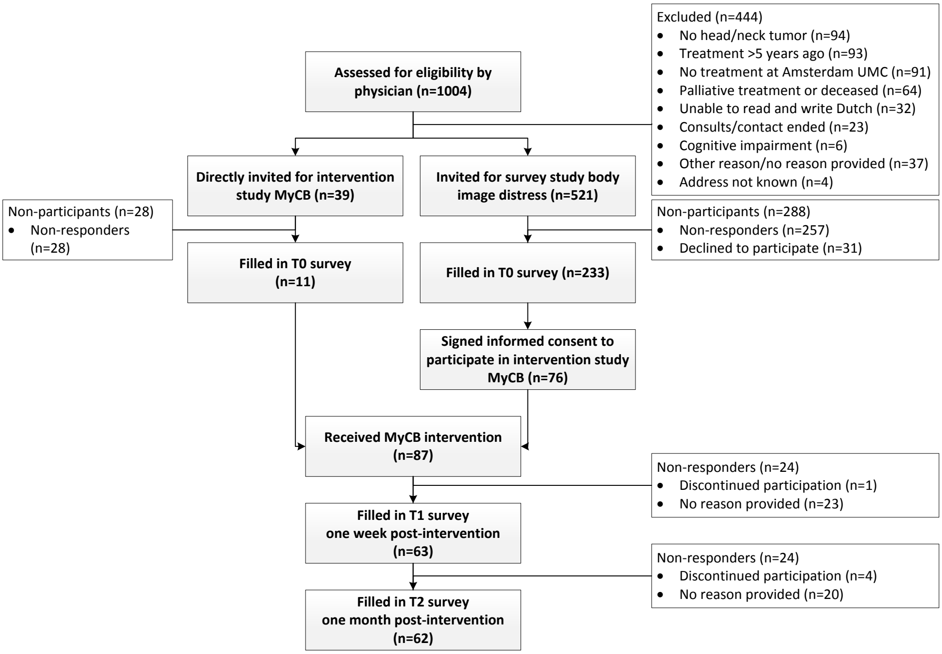

Figure 1. Flow diagram.

Table 1. Patient characteristics.

Characteristic	**N (%)**		
	Participants MyCB (n = 87)	**Participants MyCB (reach analyses)** [a] **(n = 76)**	**Non-participants (n = 157)**
Mean age in years (SD)	66 (11.2)	65 (11.8)	68 (10.1)
Gender			
Male	58 (67%)	51 (67%)	103 (66%)
Female	29 (33%)	25 (33%)	54 (34%)
Married/in a relationship[b]			
Yes	63 (72%)	55 (72%)	117 (75%)
No	23 (27%)	21 (28%)	40 (26%)
Education level			
Lower	28 (32%)	26 (34%)	21 (13%)
Middle	39 (45%)	33 (43%)	78 (50%)
Higher	20 (23%)	17 (22%)	58 (37%)
Work situation			
Employed	21 (24%)	19 (25%)	49 (31%)
Unemployed/retired	66 (76%)	57 (75%)	108 (69%)
Tumor site			
Oral cavity	17 (20%)	17 (22%)	34 (22%)
Oropharynx	20 (23%)	17 (22%)	40 (26%)
Hypopharynx	5 (6%)	2 (3%)	10 (6%)
Larynx	29 (33%)	25 (33%)	39 (25%)
Other	16 (18%)	15 (20%)	34 (22%)
Tumor stage [c]			
I/II	33 (38%)	30 (40%)	73 (47%)
III/IV	47 (54%)	39 (51%)	81 (53%)
HPV positive (oropharyngeal cancer)	14 (70%)	12 (71%)	28 (70%)
Time since treatment, years (median) (IQR)	3.3 (2.5-4.4)	3.3 (2.5-4.6)	3.3 (2.1-4.4)
Single treatment	35 (40%)	31 (41%)	80 (51%)
Surgery	16 (46%)	15 (48%)	47 (49%)
Among which C0-2 laser	11 (69%)	11 (73%)	22 (47%)
Radiotherapy	19 (54%)	16 (52%)	33 (41%)
Combination treatment	52 (60%)	45 (59%)	77 (49%)
Chemoradiotherapy	19 (37%)	16 (36%)	35 (45%)
Surgery and (chemo)radiotherapy	33 (63%)	29 (64%)	42 (55%)
Reconstruction			
None	15 (31%)	15 (34%)	30 (34%)
Primary closure	22 (45%)	18 (41%)	29 (33%)
Surgery with reconstruction	12 (25%)	11 (25%)	30 (34%)
Neck surgery			
Yes	26 (53%)	21 (48%)	41 (46%)
No	23 (47%)	23 (52%)	48 (54%)
Surgery extent			
Small	13 (27%)	13 (30%)	24 (27%)
Moderate	9 (18%)	9 (21%)	21 (24%)
Large	13 (27%)	12 (27%)	24 (27%)
Very large	14 (29%)	10 (23%)	20 (23%)

[a] n = 11 patients were excluded for the reach analysis, because they were directly invited for the MyCB intervention study

[b] n = 1 missing in participants MyCB

[c] n = 7 missing in participants MyCB and n = 3 missing in non-participants

Reach of MyCB

The reach was 15% (76/521) to 33% (76/233). In total, 59% of participants chose the booklet and 41% chose the website. Factors associated with the reach are shown in Supplementary Table S1. Factors that were significantly associated with the reach of MyCB in the multivariate analysis, were education level (p = 0.001), social eating problems (p = 0.003) and wound healing problems (p = 0.041). MyCB was more likely to reach patients who were lower educated than middle or higher educated patients. MyCB was also more likely to reach patients with more social eating problems and patients with fewer wound healing problems. The model explained 15% (Nagelkerke R^2) of the variance in reach.

Effects of MyCB

In total, 9 patients (10%) showed a clinically relevant improvement in body image distress of 3 points between T0 and T2. Across all 87 patients, the difference in BIS mean scores compared to T0 was not statistically significant at T1 (p = 0.89) and T2 (p = 0.73). The sensitivity analysis among MyCB users (n = 41) showed also no significant effect on body image distress. The course of body image distress over time was not significantly different (p = 0.38) between HNC patients with a BIS score ≥ 8 and those with a BIS score < 8 (Figure 2). Self-compassion improved significantly during follow-up until T2 (p = 0.003). No effects were observed on other secondary outcomes (Table 2). No factors were associated with reduced body image distress (Supplementary Table S2).

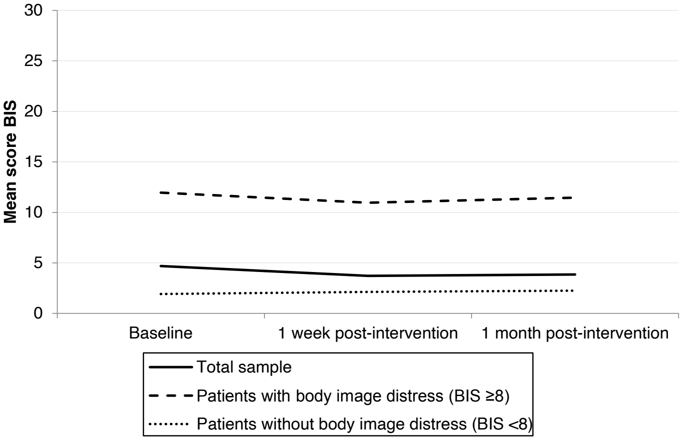

Figure 2. The course of body image distress of the total sample (n = 87); patients with BIS score ≥ 8 (n = 24) and patients with BIS score < 8 (n = 63).

Table 2. Descriptives and linear mixed model analyses at baseline (T0), one week- (T1) and one month (T2) post-intervention.

	Descriptives	**Linear mixed model analysis**		
	Mean (SD)	**Estimated mean change from baseline**	**95% CI**	**P-value**
Body image distress (range 0-30)				0.89
T0	4.7 (5.4)	n/a [a]		
T1	3.7 (4.8)	-0.1	-0.8 to 0.7	
T2	3.9 (4.8)	0.1	-0.6 to 0.9	
Sensitivity analysis MyCB users				0.62
T0	3.1 (3.8)	n/a		
T1	2.9 (3.2)	-0.2	-1.1 to 0.6	
T2	3.1 (3.8)	0.1	-0.7 to 1.0	
Body appreciation (range 1-5)				0.43
T0	4.0 (0.7)	n/a		
T1	4.1 (0.6)	0.1	0.0 to 0.1	
T2	4.0 (0.6)	0.0	-0.1 to 0.1	
Self-compassion (range 1-7)				**0.009**
T0	4.7 (0.8)	n/a		
T1	5.0 (1.0)	0.2	0.0 to 0.3	
T2	5.1 (1.0)	0.2	0.1 to 0.4	
Psychological distress (range 0-42)				0.67
T0	10.8 (7.9)	n/a		
T1	9.2 (7.2)	-0.3	-1.1 to 0.5	
T2	10.0 (7.5)	0.1	-0.8 to 0.9	
Health-related quality of life (range 0-100)				0.84
T0	79.8 (16.6)	n/a		
T1	82.0 (13.6)	-0.1	-0.3 to 0.2	
T2	81.4 (15.2)	-0.1	-0.3 to 0.2	
Problems with social contact (range 0-100)				0.07
T0	8.4 (22.3)	n/a		
T1	9.5 (21.1)	0.3	-0.1 to 0.7	
T2	4.8 (13.3)	-0.2	-0.6 to 0.2	
Problems with wound healing (range 0-100)				0.78
T0	7.4 (18.0)	n/a		
T1	8.1 (19.7)	0.1	-0.4 to 0.6	
T2	6.4 (15.8)	0.0	-0.5 to 0.5	
Sexually active (yes/no)				McNemar Test (n = 54) 0.77
T0 (n = 79)	Yes n = 43 (54%) No n = 36 (46%)			
T2 (n = 57)	Yes n = 23 (40%) No n = 34 (60%)			
Reported sexual problems among sexually active patients (yes/no)				McNemar Test (n = 18) 1.00
T0 (n = 43)	Yes n = 24 (56%) No n = 19 (44%)			
T2 (n = 23)	Yes n = 13 (57%) No n = 10 (43%)			

Significant differences (p<0.05) are presented in bold font. [a] not applicable.

Evaluation MyCB

Table 3 presents the MyCB evaluation results. In summary, patients primarily participated because they were asked to / for research purposes (89%). Almost half of the patients spent between 15-30 minutes undertaking the writing activity (49%). The majority (78%) was able to express concerns regarding their body or appearance "quite a bit" or "very much". Most patients found MyCB clear, complete, meeting expectations, useful and clarifying. A small group reported that MyCB was "quite a bit" or "very much" confronting (31%), or bothersome (12%). The most reported value of MyCB was learning that other people also have body distress (33%). In total, 42% reported having gained insights to deal with body/ appearance after cancer. In the open-ended questions, patients shared thoughts on the added value of MyCB, gained insights, unnecessary parts and additional tips. MyCB was rated with a 7.2 on a scale of 0-10 for satisfaction.

Table 3. Answers to the evaluation questions of MyCB.

Questions and answer options	n	%	Open answers
1. What was the (most important) reason to participate in this research? (multiple answers possible)			
I was asked to participate in this research	56	89%	
I wanted to tell my story	11	18%	
To feel better about my body / appearance	3	5%	
Other reason	12	19%	
2. How much time did you spend to the writing activity?			
Less than 15 minutes	9	10%	
Between 15 and 30 minutes	30	49%	
Between 30 minutes and 1 hour	18	30%	
Between 1 hour and 1.5 hour	6	10%	
Between 1.5 hour and 2 hours	0	0%	
More than 2 hours	1	2%	
3. In the writing activity, were you able to express everything that you were concerned about regarding your body / appearance?			
Not at all	1	2%	
A little	12	20%	
Quite a bit	26	44%	
Very much	20	34%	
4a. Did you find the writing activity clear?			
Not at all	4	7%	
A little	10	17%	
Quite a bit	34	58%	
Very much	11	19%	
4b. Did you find the writing activity complete?			
Not at all	3	5%	
A little	10	18%	
Quite a bit	30	54%	
Very much	13	23%	

Table 3 continued.

Questions and answer options	n	%	Open answers
4c. Did the writing activity meet your expectations?			
Not at all	4	7%	
A little	11	19%	
Quite a bit	32	55%	
Very much	9	16%	
4d. Did you find the writing activity useful?			
Not at all	3	5%	
A little	13	22%	
Quite a bit	26	45%	
Very much	16	28%	
4e. Did you find the writing activity clarifying?			
Not at all	8	14%	
A little	11	19%	
Quite a bit	26	45%	
Very much	13	22%	
4f. Did you find the writing activity confronting?			
Not at all	25	42%	
A little	16	27%	
Quite a bit	11	18%	
Very much	8	13%	
4g. Did you find the writing activity bothersome?			
Not at all	40	68%	
A little	12	20%	
Quite a bit	4	7%	
Very much	3	5%	
5. What do you think is the added value of the writing activity? (multiple answers possible)			
I better understand feelings about my body and my appearance	6	10%	
I am better able to distance myself from my feelings, thoughts and/or behavior about my body	10	17%	
I have become kinder to myself and my body	7	12%	
I know that other people have similar experiences (for example, not feeling comfortable about their appearance or body)	20	33%	
None of the above	19	32%	
Other comments	14	22%	• "I realized that I can trust my body if something is 'wrong', my body gives me a clear signal." • "No matter how much you write compassionately about your body/defects, they will not come back." • "Advantage: writing about what concerns you unconsciously. Disadvantage: being confronted with what has happened, reliving it. Trying to clear your head, also from things that have nothing to do with cancer." • "The writing activity is about people's opinion. Personally I prefer facts."

Table 3 continued.

Questions and answer options	n	%	Open answers
6. As a result of the writing activity, did you gain insight(s) for dealing with your body / appearance after cancer?			
Yes	23	42%	
No	32	58%	
7. Can you describe which insight(s) you have received?			
			• "Be kind to yourself. Accept your body as it is. You're still the same person. Appearance is inferior. Be yourself." • "That I have constant pain and fatigue and that I've become insecure." • "That [after the treatment] I am a healthy and privileged person."
8. Did you find certain parts unnecessary and, if so, which?			
			• "It was not applicable to my situation." • "I have no changed appearance, so the questions were difficult to answer." • "I found the prompts too vague. Shorter, more guided questions would be more effective. It was multi-interpretable now."
9. Have you missed any parts and, if so, which ones?			
			• "The questions are too general. I had a tumor in my throat and therefore problems with swallowing and taste." • "Questions about a changed diet." • "Questions about a voice prosthesis." • "Behavior change. I would like to learn how to get angry and how to take care of myself." • "How I experience my rehabilitation process, is it taking too long?" • "A clear description of the patients' perspective with regard to his past."
10. Do you have any additional tips and / or comments?			
			• "It was a pleasant activity for me, to fill in the writing activity. It gives you a moment of reflection on all events. The entire cancer trajectory passes you by like a rollercoaster. A moment of reflection." • "It seems to me that the writing activity in this form is not suitable for laryngectomized patients. This is due to the relatively difficult formulation of the questions asked." • "It has not changed anything for my acceptance / well-being. I struggle daily with the consequences! I am trying to enjoy life but it is not easy." • "I would opt for a more guiding way of asking. This was far too open-ended and therefore not stimulating enough to achieve true self-reflection."
11. In sum, how do you grade the writing activity?			
0: very poor to 10: very good (mean, SD)	7.2 (1.5)		

DISCUSSION

This pilot study investigated the reach of the structured writing activity MyCB among HNC patients and its effect on body image distress. The reach of MyCB was 15-33%. MyCB especially reached patients with a lower education, more social eating problems and fewer wound healing problems. No significant change in body image distress between baseline and post-intervention was found, nor in body appreciation, psychological distress, HRQOL, HNC symptoms and sexuality. Self-compassion significantly increased between baseline and one month post-intervention.

The reach of MyCB (15-33%) fell within the expected range (13-24%)[10,23,24], and the upper range is higher. A possible explanation for the higher upper range is that above-mentioned studies have explored the need for care regarding body image, which provides only an indication for the actual reach of a body image intervention. Also, HNC patients prefer written material as a source of supportive care for body image distress (like MyCB), compared to counseling, a support group, mental health specialist, or computerized information[10].

As expected, higher body image distress was univariately associated with the reach of MyCB. However, other factors were more strongly associated with the reach in the multivariable analysis. MyCB especially reached lower educated HNC patients, which is a positive finding because studies on psychosocial interventions tend to mostly reach highly educated cancer patients[47]. This might be related to the fact that patients could choose a booklet version, since lower educated cancer patients are less likely to use internet[48].

The absence of change in body image distress did not support our hypothesis that MyCB would reduce body image distress in HNC patients, nor the findings from a previous RCT on MyCB[22]. This might be explained by the low level of body image distress pre-intervention: a mean BIS score of 4.7. This is in contrast with the RCT (mean BIS score 11.5), where patients were only included if they experienced at least one negative event related to bodily changes after breast cancer. The absence of change may be caused by a floor effect[49]. However, we compared HNC patients with a BIS score ≥ 8 to those with a BIS score < 8 and found no significant difference in the course of body image distress, which indicates that a floor effect is no plausible explanation.

Another explanation for the absence of change may be the difference in body image symptoms between breast cancer and HNC patients. For HNC patients, damaged essential body functions like speech and swallowing with a large impact on social life are central aspects of body image distress[8]. Breast cancer and its treatment does not impair essential body functions as profoundly, so disfigurement may be a more central aspect of body image distress. Possibly, self-compassion positively influences thoughts and feelings related to disfigurement (attractiveness, appearance) but not thoughts and feelings related to dysfunction in speech and swallowing.

Results showed that MyCB has a positive influence on self-compassion. This is consistent with the previous RCT[22]. In that RCT, the significant effect of MyCB on body image distress was mediated by self-compassion. It was suggested that a high level of self-compassion would be a protective factor for breast cancer patients at risk of experiencing body image distress. However, this technique does not seem to apply to HNC patients.

HNC patients rated satisfaction with MyCB as 7.2/10. Additional results showed that HNC patients were generally positive about MyCB, with 78% indicating they were able to express everything they were concerned about regarding their body. In contrast, 58% indicated they did not gain insights in dealing with body/appearance changes after cancer, possibly related to difficulties that some patients indicated in interpreting the prompts within the context of their specific treatment. For HNC patients, MyCB would likely need to be modified to better reflect functional bodily changes following HNC treatment, rather than appearance changes, and MyCB may be more suitable to provide benefits that are existential in nature[50], like self-compassion.

A limitation of this study is that we built on the previous RCT[22] among breast cancer patients, and did not include a control group to compare outcomes in our study. Another limitation is that this was a single-center study, in one country. Therefore, results should be interpreted with caution, and we can only conclude that it is likely that MyCB is effective in HNC patients to improve self-compassion.

For the purpose of alleviating body image distress in HNC patients, MyCB in its current form is not the preferred intervention due to absence of an effect. However, MyCB can be useful to improve self-compassion in HNC patients. Having a kind and non-judgmental perspective towards oneself and recognizing that suffering is part of the shared human experience, may provide some alleviation to the burden of cancer.

Due to the paucity of effective body image interventions for HNC patients, more research is needed to develop and investigate such interventions. Body image distress in HNC patients is mainly caused by difficulties resulting from physical dysfunction[8], whereby HNC patients with speech and swallowing problems are those most likely to avoid social contact[5]. Therefore, if deficits cannot be resolved, interventions could focus on learning how to cope with deficits, especially in social situations.

Conclusion

In conclusion, MyCB reached up to a third of HNC patients, especially those with a lower education, more social eating problems and fewer wound healing problems. MyCB did not reduce body image distress, but is likely to improve self-compassion sustaining up to one month after intervention use.

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SUPPLEMENTARY MATERIAL

Supplementary Table S1. Univariate and multivariate regression of factors associated with the reach, and descriptive statistics.

	Univariate		Multivariate	
Variable	**OR [95% CI]**	**P-value**	**OR [95% CI]**	**P-value**
Age	0.98 [0.95-1.00]	0.10		
Gender		0.82		
Female	1			
Male	1.1 [0.60-1.9]			
Married/ in a relationship		0.73		
Yes	1			
No	1.1 [0.60-2.1]			
Education level		**0.001**		**0.001**
Lower	1		1	
Middle	0.34 [0.17-0.69]		0.32 [0.15-0.69]	
Higher	0.23 [0.11-0.52]		0.23 [0.11-0.52]	
Work situation		0.38		
Employed	1			
Unemployed/retired	1.3 [0.71-2.5]			
Tumor site		0.59		
Oral cavity	1			
Oropharynx	0.85 [0.38-1.9]			
Hypopharynx	0.40 [0.08-2.0]			
Larynx	1.3 [0.59-2.8]			
Other	0.88 [0.38-2.1]			
Tumor stage		0.59		
I/II	1			
III/IV	1.2 [0.66-2.1]			
Time since treatment	1.1 [0.89-1.3]	0.44		
Treatment modality		0.24		
Surgery	1			
Radiotherapy	1.5 [0.66-3.5]			
Chemoradiotherapy	1.4 [0.63-3.3]			
Surgery plus (chemo)radiotherapy	2.2 [1.02-4.6]			
Surgery extent [a]		0.98		
Very large	1			
Large	1.00 [0.36-2.8]			
Moderate	0.86 [0.29-2.6]			
Small	1.1 [0.39-3.0]			
Reconstruction		0.52		
None	1			
Primary closure	1.2 [0.53-2.9]			
Surgery with reconstruction	0.73 [0.29-1.7]			
Neck surgery		0.86		
No	1			
Yes	1.1 [0.52-2.2]			

Supplementary Table S1 continued.

	Univariate		Multivariate	
Variable	**OR [95% CI]**	**P-value**	**OR [95% CI]**	**P-value**
HPV [b]		0.69		
Negative	1			
Positive	0.77 [0.21-2.8]			
Body image distress	1.1 [1.01-1.1]	**0.018**		
Body appreciation	0.99 [0.95-1.03]	0.49		
Quality of life [c]	0.73 [0.60-0.89]	**0.002**		
HNC symptoms [c]				
Fear of progression	1.2 [1.04-1.3]	**0.011**		
Dry mouth and sticky saliva	1.1 [0.97-1.2]	0.20		
Pain in the mouth	1.2 [1.04-1.4]	**0.012**		
Problems with senses	1.05 [0.95-1.2]	0.38		
Problems with shoulder	1.00 [0.88-1.1]	0.94		
Skin problems	1.1 [0.95-1.3]	0.20		
Social eating	1.2 [1.1-1.3]	**0.003**	1.2 [1.08-1.4]	**0.003**
Speech	1.1 [1.02-1.2]	**0.024**		
Swallowing	1.2 [1.04-1.3]	**0.010**		
Problems with teeth	1.2 [1.02-1.3]	**0.021**		
Coughing	1.1 [1.01-1.2]	**0.040**		
Swelling in the neck	1.2 [1.02-1.3]	**0.023**		
Neurological problems	1.1 [0.97-1.2]	0.20		
Trismus	1.1 [0.99-1.2]	0.07		
Social contact	1.1 [0.96-1.4]	0.15		
Weight loss	1.04 [0.93-1.2]	0.52		
Problems with wound healing	0.99 [0.85-1.1]	0.84	0.83 [0.69-0.99]	**0.041**
Psychological distress	1.04 [1.00-1.1]	0.052		
Symptoms of depression	1.1 [0.98-1.1]	0.13		
Symptoms of anxiety	1.1 [1.00-1.1]	**0.040**		
Self-compassion	0.86 [0.64-1.2]	0.32		
Sexuality		0.97		
No sexual activity	1			
Sexually active without sexual problems	0.95 [0.46-1.9]			
Sexually active with sexual problems	0.92 [0.47-1.8]			

Significant differences ($p < 0.05$) are presented in bold font.

EORTC QLQ-C30/HN43 30-item core European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire/head and neck cancer, 43 items, *HADS* Hospital Anxiety and Depression Scale, *SCS-SF* Self Compassion Scale – Short Form.

[a] Small: C02-laser of vocal fold, lip excision, ear amputation, skin excision small nose tumor. Moderate: excision of sublingual/submandibular salivary gland, transoral excision, lip surgery with reconstruction, partial sinus resection, skin excision with local reconstruction, neck surgery. Large: parotidectomy with neck surgery, marginal and segmental mandibular resection, transoral excision with reconstruction, extensive sinus surgery, maxillectomy, skin excision with neck surgery or reconstruction. Very large: commando procedure, laryngectomy, lateral temporal bone surgery.

[b] n = 54 oropharyngeal cancer patients with a known HPV status.

[c] OR per 10 point increase in subscale.

Supplementary Table S2. Univariate regression analysis of factors associated with reduced body image distress (improvement of 3 points or more).

Variable	OR [95% CI]	P-value
Age in years		0.13
<67	1	
≥67	0.29 [0.06-1.5]	
Gender		1.00
Female	1	
Male	1.00 [0.23-4.3]	
Married/ in a relationship		0.29
Yes	1	
No	0.31 [0.04-2.7]	
Education level		0.94
Lower	1	
Middle/higher	0.94 [0.22-4.1]	
Work situation		0.37
Employed	1	
Unemployed/retired	0.5 [0.11-2.3]	
Tumor site [a]		0.14
Oral cavity/oropharynx	1	
Hypopharynx/larynx	0.19 [0.02-1.8]	
Tumor stage		0.34
I/II	1	
III/IV	2.3 [0.43-12.0]	
Time since treatment		0.26
<3 years	1	
≥3 years	2.6 [0.50-13.2]	
Treatment modality		0.09
Single treatment	1	
Combination treatment	6.2 [0.74-51.8]	

[a] Other tumor sites are excluded from the analysis.

Chapter 7

General discussion

The main objective of this thesis was to investigate body image and sexuality in head and neck cancer (HNC) patients. We focused on the identification and prevalence of body image distress and sexual issues, and examined interventions that could alleviate body image distress and sexual issues. In this chapter, the main findings are discussed and put into perspective compared to prior research, followed by a reflection on the methodological strengths and limitations of the studies in this thesis. Furthermore, implications for clinical practice and directions for future research are presented. The chapter ends with a main conclusion.

MAIN FINDINGS

The first part of this thesis (Chapters 2, 3 and 4) focused on the identification of body image distress and sexual issues in HNC patients. A systematic review on the measurement properties of the Body Image Scale (BIS) showed that this patient-reported outcome measure (PROM) is a reliable instrument to identify body image distress in cancer patients (Chapter 2). However, evidence on the validity of the BIS can be further optimized. Using the BIS as outcome measure, the prevalence of body image distress in HNC patients was 13-20% (Chapter 3). HNC patients who had symptoms of depression, problems with social contact, who were younger, had more extensive surgery or problems with wound healing, were more at risk of having body image distress. Patients reported their experiences on how a changed body had a negative impact on social functioning, e.g. difficulties with eating, drinking and talking in a public situation. To investigate the course of sexual issues in HNC survivors over time, a longitudinal study was performed (Chapter 4). Results showed that 37% of patients reported less sexuality directly after diagnosis, which rose to 60% six weeks after treatment, and returned to baseline level a year after treatment and further on. Patients who were older, who had trouble with social contact, weight loss, or constipation before treatment, were more at risk of having less sexuality over time. Also, female patients and those with poor social functioning after treatment were more at risk of less sexuality from six months after treatment and onwards.

The second part of this thesis (Chapter 5 and Chapter 6) described studies that investigated the effect of supportive care interventions on body image distress and sexual issues in HNC patients. A stepped care intervention that proved to be effective to reduce psychological distress, was not effective to improve sexuality in HNC patients (Chapter 5). Next, the reach and effectiveness of the intervention “My Changed Body” (MyCB) targeting body image distress in HNC patients was investigated (Chapter 6). This study showed that MyCB could potentially reach 15-33% of HNC patients, especially lower educated patients, those who have problems with social eating, and those with better wound healing. The study also showed that it is likely that MyCB is not effective in reducing body image distress, but is effective to improve self-compassion.

DISCUSSION OF THE MAIN FINDINGS

Identifying body image distress in HNC patients

The Body Image Scale (BIS) is the most often used instrument for measuring body image distress in cancer patients[1]. In Chapter 2, the BIS showed to be a reliable instrument to identify body image distress. Although most measurement properties of the BIS were found to be adequate, improvements can be made to optimize the validity of the BIS. These improvements include optimizing evidence regarding measurement error, hypothesis testing for construct validity, and responsiveness. Also, it should be noted that the BIS, designed for use in all types of cancer patients, is evaluated mainly among breast cancer patients. Future research on the measurement properties of the BIS should include HNC patients. In addition, damaged vital functions in HNC patients, like speech and swallowing, play an important role in relation to body image[2]. However, in the BIS, the functional aspect of body image is covered by items like “Have you been feeling the treatment has left your body less whole?” and “Have you felt dissatisfied with your body?”[3]. It is worthwhile to further investigate if the unique functional impairments of HNC patients are fully covered, or that the BIS should incorporate new items identifying functional aspects of body image in HNC patients.

This thesis made it clear that a significant number of people struggle with body image distress and sexual issues after HNC (Chapters 3 and 4). In the general population, 26.5% evaluate their physical appearance negatively[4], but this is much less severe than actual body image distress described in HNC patients. Reported sexual interest and enjoyment in the general population as measured with sexual items derived by the EORTC (European Organization for Research and Treatment of Cancer) Quality of Life Group item bank, is 46 and 72 respectively (range 0-100; higher scores indicate more sexual interest and enjoyment)[5]. It is important to keep in mind that body image distress and sexual issues are also present in people without HNC.

To better understand factors that are associated with body image and sexuality in HNC patients, the conceptual framework “Coping with disfigurement and dysfunction after head and neck cancer surgery” by Rhoten and colleagues[6] can be used. This framework conceptualizes body image distress in HNC patients. Particularly disfigurement and dysfunction are thought to result in body image distress. Disfigurement can be present in the form of scars and burns; removed skin, soft tissue or bones; and damaged nerves; all of which can result in a different facial contour and expression. Dysfunction consists of general functional impairment such as weakness and fatigue; loss of function such as speech, swallowing and drooling; and musculoskeletal dysfunction of the jaw, shoulders or neck[6]. Body image distress may be present along the cancer trajectory, which means: the timeline from diagnosis and treatment to post-treatment (for patients treated with curative intent). Patient characteristics, social factors and environmental factors can moderate the effect of dysfunction and disfigurement on body image distress. For example, depressive symptoms can result in increased levels of body image distress, and support from loved ones can result in decreased levels of body image distress. Some patients may accept the body changes over time, which is described as “reintegration”. When the process of reintegration is successful, it can result in positive social outcomes, psychological outcomes, and quality of life.

The model by Rhoten and colleagues[6] is adapted from two often used frameworks: the stress and coping framework (coping with stress is a gradual process toward the specified goal of body image reintegration)[7] and the fear-avoidance framework of psychosocial difficulties (fear is likely to lessen with continuing exposure and to increase with avoidance)[8]. Since these frameworks focus on specific aspects of body image in HNC patients, Rhoten and colleagues aimed to create a more global framework that informs about the causes, mediators and moderators of body image in HNC[6]. Although evidence for this conceptual framework is still low, the general approach is useful to discuss the findings of this thesis, which also examined body image, sexuality and associated factors in a broader context.

Based on the findings in this thesis, the framework can be expanded by incorporating sexuality and related concepts (Figure 1). Sexuality was added as a central concept, which contains aspects of sexuality that were measured in this thesis (sexual interest, enjoyment, activity and reported problems). Also, psychological distress was added as an associated factor. It should be noted that causality of the associated factors cannot be proven. For example, future prospective research may prove that psychological distress is an outcome of body image distress and should be added as an outcome in the model. Four keypoints (1-4) of the expanded framework are used to discuss the findings of this thesis in the next paragraphs.

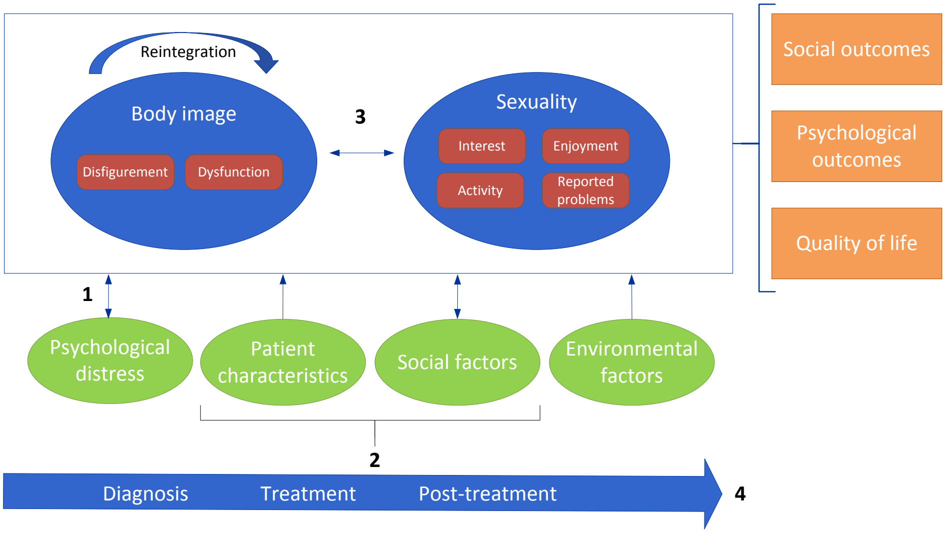

Figure 1. The adjusted conceptual framework from Rhoten and colleagues[6]

Keypoint 1. Psychological distress is strongly associated with body image and to a lesser extent, with sexuality. Psychological distress -in particular symptoms of depression- was strongly associated with body image distress in HNC patients (Chapter 3), which is consistent with earlier findings[9-11]. This association might be explained by distress related to often permanent losses in basic functioning, such as speech and swallowing. Problems with communication, inability to return to work and to socialize, and disrupted intake and enjoyment of food, affect psychological wellbeing[2]. Moreover, a changed facial appearance can disrupt feelings of integrity and identity[12]. It is not surprising that these losses in body function and appearance induce grief and profound psychological distress[2]. In turn, feeling depressed or anxious can also increase body image distress through experiencing negative thoughts and feelings towards the body. Since the causal direction remains unclear, the arrows between body image distress and psychological distress in the framework point in both directions.

Psychological distress was not significantly associated with sexuality in HNC patients (Chapter 4). Only a univariate association was found between psychological distress and sexual interest and enjoyment from six months after treatment and onwards. This is in contrast to other research that found a clear link between psychological distress and sexual problems in colorectal and breast cancer patients, and in a non-cancer population[13-15]. In sum, psychological distress and sexuality are connected to each other in this model, but more in-depth research is needed in which way these factors actually influence each other. More support was found for the connection between sexuality and other factors, described in the next key point.

Keypoint 2. Patient characteristics are potential causal factors, and social factors are associated with body image distress and sexuality. A variety of patient characteristics and social factors were significantly associated with body image distress and sexual issues (Chapter 3 and 4). Given the nature of the study design (cross-sectional and longitudinal), no firm conclusion on causality can be drawn, but it seems likely that younger age, extensive surgery and problems with wound healing are causal factors of body image distress (Chapter 3); and older age, female gender, weight loss and constipation are causal factors of sexual issues (Chapter 4). The factor “problems with social contact” was associated with body image distress and sexuality; and “poor social functioning” after treatment was associated with sexuality. However, more (prospective) research is needed on the direction of the associations between problems with social contact and body image distress, and between poor social functioning, problems with social contact and sexual issues. The identification of these associated factors will offer new insight into what contributes to body image distress and sexual issues in HNC patients.

Keypoint 3. A fragile link between body image distress and sexuality. In Chapter 4, the course of sexuality was worse for patients who had problems with social contact, which was measured with body image-related questions, e.g. being bothered by appearance and trouble with going out in public. In Chapter 3, however, sexuality of HNC patients was not associated with body image distress. A possible explanation for these contradictory findings could be that different aspects of sexuality were measured. In Chapter 4, sexuality was measured as the degree of sexual interest and enjoyment. The emphasis was therefore on how sexuality was experienced. In Chapter 3 sexuality was evaluated as being sexually active (yes or no), and as the total degree of desire, arousal, lubrication, orgasm, satisfaction, pain (women) and erectile function (men). Here, the focus was mainly on sexual function. It could be that body image distress is associated with how sexuality is experienced, but is not directly associated with sexual function. This suggestion is supported by previous qualitative research on sexuality and intimacy after HNC treatment. HNC patients described how their changed body negatively influenced their sexual experiences. For example, no longer being able to embrace and kiss due to bodily changes including lack of sensation, mouth problems, or wearing a PEG tube, influenced sexuality[16,17]. Patients also reported no longer feeling sexually attractive and not feeling desired by their partner, which reduced the quality of the emotional connection[17].

Another possible explanation is that although the prevalence of body image distress in HNC patients (13-20%) is substantial, some patients may have body dissatisfaction that is not related to head and neck cancer. Body image distress is common in the general population as well, with 26.5% evaluating their physical appearance negatively[4]. Although the nature of the body image distress in HNC patients may differ from that of healthy individuals, the presence of general body image distress may have attenuated the association between HNC specific body image distress and sexuality.

Key point 4. Body image distress and sexual issues can be present along the cancer trajectory. In Chapter 4, results showed that this is indeed the case for sexual issues. Sexual issues were present all over the cancer trajectory, with a peak directly after treatment. The finding that sexual problems are more prominent in certain stages of the disease (particularly in the first months after treatment), is in line with other health-related quality of life symptoms in HNC patients[18]. With regard to body image distress, results from Chapter 3 showed that time since treatment was not associated with the prevalence of body image distress among HNC patients after treatment. It seems that for some HNC patients, body image distress and sexual issues do not disappear over time. This is in accordance with existing literature. In a study investigating body image among breast cancer patients, some patients showed steadily deteriorating scores[19]. Continuing attention is needed for these issues and a part of the HNC patients need supportive care for body image distress and sexual issues along the cancer trajectory. As per the findings in this thesis, particularly younger HNC patients with symptoms of depression and problems with social contact, who had more extensive surgery or wound healing issues deserve continued attention regarding body image distress, whereas older patients (particularly female) who are less socially skilled and who are known to have problems with weight loss or constipation should be subject to specific care with respect to sexuality.

Interventions targeting body image and sexuality in HNC patients

Chapter 5 showed that a stepped care intervention that improves psychological distress in HNC patients, did not result in an additional improvement of sexuality. This is consistent with Chapter 3, where no significant association was found between depressive symptoms and the course of sexuality in HNC patients. The results suggest that interventions should specifically target sexuality to be successful on sexual outcomes. Evidence regarding effective sexual interventions in HNC patients is scarce[20]. In breast cancer patients with sexual dysfunction, internet-based cognitive behavioral therapy showed to be effective in improving sexual functioning, body image and menopausal symptoms[21]. It would be interesting to investigate if this intervention is beneficial for HNC patients with sexual problems as well. Another strategy could be to improve adequate referral, for example to a sexologists or psychologist, in order to decrease sexual problems in HNC patients. In general, health care professionals (clinicians, specialized cancer nurses) seem hesitant to talk with patients about sexual problems because they feel unprepared, embarrassed or scared to do so[22]. Hoole and colleagues[20] suggested that they could use the Permission, Limited Information, Specific Suggestions, Intensive Therapy (PLISSIT) model to introduce the topic of sexuality with their patients and to help make an adequate referral. It starts with opening the discussion; then providing information about causes of sexual problems due to cancer; next specific suggestions can be given and the last step is to refer to intensive therapy.

The results of Chapter 6 showed that although the MyCB intervention improved self-compassion, it did not reduce body image distress in HNC patients. This is in contrast to a previous randomized controlled trial (RCT) among breast cancer patients, where a considerable reduction in body image distress was observed after the writing activity MyCB[23]. It is possible that in HNC patients, self-compassion is not inversely related with body image distress, in contrast to previous findings with breast cancer patients[24]. Other mechanisms might be involved. For instance, the physical consequences of HNC treatment are more publicly noticeable and may therefore affect social interactions more directly than those of breast cancer patients. Two recent studies which focused on improving appearance with cosmetic rehabilitation (make-up supplies, cosmetic education), did not improve body image[25-27].

Perhaps interventions for HNC patients should not just focus on improving physical appearance, but on dealing with difficult social situations, caused by functional deficits like speech and eating problems. In Chapter 3, respondents described spilling food through the nose while being in company of strangers, the inability to have a conversation at noisy parties because of voice problems, or being ignored because of intelligibility difficulties. Interventions that focus on dealing with those social situations may involve learning to manage being stared at or being ignored, and how to take initiative in social encounters. Two previous studies that used this approach already showed some promising results. The first study investigated a psychoeducational intervention aimed at managing appearance concerns in social situations among oral cancer patients, showing positive results with regard to body image[28]. The second study investigated a comparable nurse-delivered social rehabilitation program for HNC patients, which showed to decrease social embarrassment and improved social functioning[2,29]. The studies focused on appearance concerns, not on functional deficits. If difficulties with voice and eating are also incorporated, such an intervention might be helpful in those particular social situations. More research is needed to unravel the effect of such interventions aiming to reduce body image distress in HNC patients.

STRENGTHS AND LIMITATIONS

A strength of this thesis is that a broad approach was used to investigate body image distress and sexual issues in HNC patients and several research techniques were used. We performed a systematic review to gain insight in the available literature in identifying body image distress with the BIS. In this study we used the newest version of the COSMIN criteria, a widely used credible method to assess psychometric properties of a measurement instrument. We also conducted a longitudinal and a cross-sectional study, which provided data on the course of body image distress/sexual issues over time as well as at a certain point in time. Moreover, we used data from a randomized controlled trial in Chapter 5, which is the gold standard in investigating the effects of an intervention.

This thesis has limitations that should be mentioned as well. First, generalizability to the general HNC population of some results may be limited. In Chapter 3, HNC patients were only included if they answered the sexuality questions at baseline. Therefore, patients who were reluctant to provide information about their sex life were not included. However, no significant sociodemographic or clinical differences between participants and non-participants were found. In Chapter 4 on the prevalence of body image distress, the response rate was low, increasing the risk of biased results. Due to privacy regulations, it was not allowed to compare characteristics between participants and non-participants. Next, we did not investigate all factors that could be associated with body image distress and sexual issues in HNC patients. For example, a considerable number of HNC patients have a history of alcohol and tobacco use. This is also a risk factor for sexual problems like erectile dysfunction. Other factors that we did not examine with regard to sexuality include socio-cultural beliefs and norms, and the quality of the partner relationship[30]. Furthermore, the presence of a comorbid disease might influence sexuality as well as body image outcomes[6]. Lastly, in Chapter 6 we performed a pilot study without incorporating a control group (because a randomized controlled trial was already conducted on this intervention, among breast cancer patients). Because of the non-randomized design of our study, the effects could be attributed to other unknown factors. Results should therefore be interpreted with caution.

IMPLICATIONS FOR CLINICAL PRACTICE

This thesis highlights the importance of identifying body image distress and sexual issues in HNC patients. Incorporating the use of patient-reported outcome measures in clinical practice makes it possible for patients and healthcare professionals to identify possible difficulties with body image and sexuality. It also creates an opportunity to start a conversation, since research has shown that patients as well as healthcare professionals are hesitant to bring up the topic of sexuality or body image themselves. An example of an instrument to screen for quality of life in cancer patients is OncoQuest[31,32]. This touch screen computer-assisted data collection system can be filled in by patients every time they visit the outpatient clinic. The outcomes can be discussed with a specialized nurse, improving adequate and timely referral to additional supportive care if needed.

The need to provide adequate supportive care is also emphasized in this thesis. For patients with sexual issues, the main recommendation is to provide interventions specifically targeting sexuality. With regard to body image distress, a self-paced writing activity based on the theory of self-compassion seems effective to improve self-compassion, but not effective to reduce body image distress in HNC patients. Therefore, other supportive care options should be considered, such as interventions that aim to improve dealing with difficult social situations. Since such an intervention is currently not available, referral to a professional is recommended. To increase optimal referral, a referral network may be helpful. Healthcare professionals can use such a network to refer patients to appropriate supportive care based on a patient's personal situation and preferences. This could be a professional like a sexologist or gynecologist in case of sexual issues, or a psychologist in case of body image distress. In recent years, an online registry of professionals (psychologists, sexologists, physiotherapist etc.) specialized in cancer has been developed in the Netherlands, which is accessible via https://kanker.nl. Healthcare professionals can use this dataset to find a suitable professional specialized in cancer for their patient.

Due to the growing number of people living with cancer, the focus on self-management of patients is also growing. This means that a patient is actively involved in managing cancer-related symptoms and finding supportive care. Oncokompas is an example of such a self-management application. It is "a web-based eHealth application that supports survivors in self-management by monitoring HRQOL and cancer-generic and tumour-specific symptoms and obtaining tailored feedback with a personalised overview of supportive care options"[33]. Oncokompas uses data from the online registry of professionals specialized in cancer mentioned in the previous paragraph. Moreover, other supportive care options are presented, like support groups or self-help interventions if symptoms are less severe. Encouraging patients to have an active role in their (sexual) life beyond cancer is an important component of clinical practice.

DIRECTIONS FOR FUTURE RESEARCH

With respect to using a patient-reported outcome measuring body image distress, it is recommended to further study measurement properties of the BIS in HNC patients specifically. The next step would be to investigate the course of their body image distress over time from diagnosis to long-term follow-up. This will provide important information about when symptoms emerge, how they develop over time and when supportive care ideally should be offered. Also, more research in developing and evaluating interventions that reduce body image distress in HNC patients is warranted. It can be useful to develop a body image intervention that focuses on coping with difficult social situations, which is also suitable for HNC patients with body image distress due to speech and eating problems.

Concerning sexuality, it would be useful to monitor the course of sexuality in more detail, for example using the Female Sexual Function Index (FSFI) for women[34] and the International Index for Erectile Function (IIEF) in men[35]. This will provide more information about the nature of the sexual problems in HNC patients. Currently, a large cohort study among 739 HNC patients and 262 caregivers is ongoing, that also collects data on sexuality using the FSFI and IIEF[36]. These data would provide new information on sexuality in HNC patients and their loved ones up to five years after treatment and also has the potential to identify a wide range of related biopsychosocial factors.

It was beyond the scope of this thesis to explore if biological factors are associated with the prevalence of sexual issues in HNC patients, but it is recommended to include biological factors in future research on sexuality in HNC patients. Biological aspects that might influence sexuality in HNC patients are for example alterations in the production of sex hormones due to chemotherapy[37,38], or the intake of medication[17]. A second suggestion is to investigate cultural and relational factors that might be associated with sexuality in HNC patients[30]. Taking into account the role of high-risk HPV infection on sexual attitudes is also recommended. Patients with HPV-induced HNC might feel guilt and responsibility since HPV is sexually transmitted. Moreover, this can raise questions about transmission to the partner and how it can be prevented[30]. Lastly, we suggest to investigate interventions specifically targeting sexuality for HNC patients with sexual problems. The internet-based intervention using cognitive behavioral therapy in breast cancer patients with sexual dysfunction might serve as an example to investigate in HNC patients[21].

MAIN CONCLUSION

A significant part of HNC patients experience body image distress and sexual problems along the treatment trajectory of HNC. The Body Image Scale can be used to monitor body image distress, but also needs more research on its psychometric properties. For monitoring sexuality, the EORTC QLQ-H&N35 sexuality subscale can be used (this subscale is also included in the revised version, the EORTC QLQ-HN43). HNC patients can be asked to complete the IIEF and FSFI if more elaborate screening is called for. Supportive care targeting body image distress and sexual issues should be an integral part of clinical cancer care. Regarding body image, a third of all HNC patients were reached by an intervention that supports them in reducing their body image distress. The self-help writing activity increased self-compassion but was not effective in reducing body image distress in this patient group. With regard to sexuality, HNC patients experience most problems directly after treatment but problems often continue to occur. A stepped care intervention targeting psychological distress was not effective to reduce sexual problems as well. More knowledge is needed on underlying mechanisms to alleviate body image distress and sexual problems, which will contribute to develop effective interventions targeting body image and sexuality in HNC patients.

With this thesis, new knowledge was obtained on the identification of body image distress and sexual issues, and on interventions that could alleviate these symptoms in HNC patients. This knowledge contributes to innovate cancer care aiming to improve quality of life of patients confronted with head and neck cancer.

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Appendices

Summary
Samenvatting (summary in Dutch)
Acknowledgments
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SUMMARY

Chapter 1 presents the general introduction of this thesis. In this chapter, information is provided on head and neck cancer (HNC), available treatment options and the effects on quality of life. HNC patients are often confronted with visible disfigurement (e.g. scars, a changed facial expression), and dysfunction (e.g. problems with speech and swallowing/eating), which can result in body image distress. HNC patients are also at risk of sexual issues, caused by a changed body and other biological, psychological and social factors. Symptoms of body image distress and sexual issues can be identified using patient-reported outcome measures (PROMs). In order to alleviate symptoms, supportive care interventions can be provided. The first part of this thesis focuses on the identification and prevalence of body image distress and sexual issues in HNC patients using PROMs. The second part of this thesis evaluates supportive care interventions targeting body image distress and sexual issues in HNC patients.

Chapter 2 describes a systematic review on the measurement properties of the Body Image Scale (BIS) in cancer patients. A systematic literature search identified 9 studies that investigated measurement properties of the BIS. Evidence was sufficient for structural validity (one factor solution), internal consistency ($\alpha = 0.86–0.96$), and reliability ($r > 0.70$); indeterminate for measurement error and responsiveness; and inconsistent for hypothesis testing. The quality of the evidence was moderate to low. No studies reported on cross-cultural validity. The BIS is a PROM with good structural validity, internal consistency, and test-retest reliability, but good quality studies on the other measurement properties are needed to optimize evidence. These studies should ideally include patients with a wider variety of cancer diagnoses, including HNC patients.

Chapter 3 examined the prevalence of body image distress and related factors in HNC patients treated with curative intent. Secondly, experiences regarding body image in daily life were investigated. Body image distress was prevalent in 13-20% among 233 HNC patients. Symptoms of depression, problems with social contact, extensive surgery, younger age, and problems with wound healing were associated with having body image distress. The model explained 67% of variance. The writings of 40 HNC patients showed that negative body image experiences were related to changes in appearance and function and resulted in problems with social functioning.

Chapter 4 investigated the course of sexual interest and enjoyment and related factors in HNC patients treated with primary (chemo)radiotherapy. HNC patients (n = 354) completed PROMs on HRQOL (health-related quality of life), HNC symptoms and psychological distress in the outpatient clinic at several time points from pretreatment until 24 months after treatment. Less sexuality is often reported: before start of treatment 37% of patients reported having less sexuality, which increased to 60% 6 weeks after treatment, and returned to baseline level from one year after treatment and onwards. Older age, trouble with social contact, weight loss, and constipation before treatment were associated with less sexuality over time. Female gender and poor social functioning at 6 month follow-up were associated with less sexuality from 6 months to two years after treatment. Using PROMs in clinical practice may help identify patients who might benefit from supportive care targeting sexuality.

Chapter 5 describes whether a stepped care program targeting psychological distress in HNC patients, is effective in reducing problems with sexual interest and enjoyment, compared to care as usual. The stepped care program consisted of 4 steps: (1) watchful waiting, (2) guided self-help via internet or a booklet, (3) face-to-face problem-solving therapy, and (4) specialized psychological interventions and/or medication. Patients were referred to the next step when symptoms of anxiety and/or depression were not relieved. In total, 76.1% of 134 HNC patients had an unmet sexual need at baseline, 24.6% had a psychiatric disorder (anxiety or depression). Stepped care did not reduce problems with sexual interest and enjoyment at any of the follow-up measurements compared to care as usual. This was neither moderated by an unmet sexual health need at baseline nor by the presence of a psychiatric disorder at baseline. Stepped care targeting psychological distress does not reduce problems with sexual interest and enjoyment in these patients. The results imply that interventions specifically targeting sexuality are needed for HNC patients who experience sexual problems.

In **Chapter 6** the reach and effects of My Changed Body (MyCB) was investigated among HNC patients treated with curative intent. MyCB is an expressive writing activity based on self-compassion. Patients first write about a negative event related to their changed appearance that made them feel bad about themselves. The next prompts encourage patients to write about this event from a self-compassionate perspective (i.e. promoting self-kindness, mindfulness and a sense of common humanity). The reach of MyCB ranged between 15-33% and was associated with lower education level, more social eating problems and fewer wound healing problems. No significant effect on body image distress was found, but self-compassion increased significantly during follow-up until 1 month after intervention use. No factors were associated with a reduced level of body image distress. Users rated MyCB with 7.2/10 on satisfaction. This pilot study showed that we reach up to a third of HNC patients, and that MyCB seems to be beneficial to increase self-compassion among HNC patients.

Chapter 7 presents the general discussion of this thesis. First, the main findings are presented, and are held into perspective with existing literature about body image and sexuality in HNC patients. An adjusted version of the conceptual framework from Rhoten and colleagues was used to discuss the findings of this thesis. In this adjusted model, body image and sexuality influence each other bi-directionally. Also, associations with psychological distress, patient characteristics and social factors are clarified. It is proposed that problems with body image and sexuality can occur along the cancer trajectory, from diagnosis until post-treatment. Next, strengths and limitations of the studies in this thesis are discussed. Implications for clinical practice and suggestions for future research are proposed. These include screening for body image and sexuality at a regular basis in clinical practice, and more research regarding effective interventions to alleviate body image and sexuality problems. The chapter ends with the conclusion that problems with body image and sexuality are a central issue for a considerable amount of HNC patients. This thesis shows directions for adequate screening and supportive care to reduce these problems and improve cancer care for HNC patients.

SAMENVATTING (SUMMARY IN DUTCH)

Hoofdstuk 1 omvat de algemene introductie van dit proefschrift. Het hoofdstuk verschaft informatie over hoofd-halskanker, beschikbare behandelopties en de effecten van de ziekte en behandeling op kwaliteit van leven. Hoofd-halskankerpatiënten krijgen vaak te maken met zichtbare uiterlijke veranderingen (zoals littekens en een veranderde gezichtsuitdrukking) en disfuncties (zoals problemen met spraak en slikken/eten), wat kan leiden tot een verstoord lichaamsbeeld. Hoofd-halskankerpatiënten lopen daarnaast risico op seksuele klachten, veroorzaakt door een veranderd lichaam en veranderingen in biologische, psychologische en sociale processen. Symptomen van een verstoord lichaamsbeeld en seksuele problemen kunnen worden geïdentificeerd met patiënt-gerapporteerde uitkomstmaten. Om symptomen te verlichten, kan ondersteunende zorg worden aangeboden. Het eerste deel van dit proefschrift richt zich op de identificatie en prevalentie van een verstoord lichaamsbeeld en seksuele problemen bij hoofd-halskankerpatiënten met patiënt-gerapporteerde uitkomstmaten. Het tweede deel van dit proefschrift evalueert ondersteunende zorginterventies gericht op lichaamsbeeld en seksualiteit bij hoofd-halskankerpatiënten.

Hoofdstuk 2 beschrijft een systematische review over de meeteigenschappen van de Body Image Scale (BIS) in patiënten met kanker. Met een systematische literatuur zoekopdracht werden 9 studies gevonden die de meeteigenschappen van de BIS hebben onderzocht. Er was voldoende bewijs voor de structurele validiteit (één-factoroplossing), interne consistentie ($\alpha = 0.86–0.96$), en betrouwbaarheid ($r > 0.70$); bewijs met betrekking tot meetfout en responsiviteit was onbepaald; en er was inconsistent bewijs omtrent hypothese toetsing. In geen enkele studie werd de cross-culturele validiteit gerapporteerd. De BIS is een patiënt-gerapporteerde uitkomstmaat met goede structurele validiteit, interne consistentie en test-hertest betrouwbaarheid. Om bewijs voor de andere meeteigenschappen te optimaliseren, zijn meer kwalitatief hoogstaande studies nodig.

In **hoofdstuk 3** werd de prevalentie van een verstoord lichaamsbeeld onderzocht en welke factoren hiermee associëren. Dit onderzoek werd uitgevoerd onder hoofd-halskankerpatiënten die werden behandeld met curatieve intentie. Daarnaast werden ervaringen in het dagelijks leven onderzocht, waardoor mensen zich slecht voelden over zichzelf of hun veranderde lichaam. Hiervoor werden kwalitatieve gegevens van een schrijfinterventie over lichaamsbeeld gebruikt. In totaal had 13-20% van de 233 onderzochte hoofd-halskankerpatiënten een verstoord lichaamsbeeld. Symptomen van depressie, problemen met sociaal contact, een uitgebreide chirurgische behandeling, jongere leeftijd en problemen met wondgenezing waren significant geassocieerd met het hebben van een verstoord lichaamsbeeld. Dit regressiemodel verklaarde 67% van de variantie van verstoord lichaamsbeeld. De beschreven ervaringen van 40 hoofd-halskankerpatiënten toonden aan dat een verstoord lichaamsbeeld gerelateerd was aan veranderingen in uiterlijk en in functie, wat resulteerde in problemen in het sociaal functioneren.

In **hoofdstuk 4** werd het beloop van seksuele interesse en seksueel plezier en factoren die hiermee associëren, onderzocht bij hoofd-halskankerpatiënten die werden behandeld met primaire (chemo)radiotherapie. Patiënten (n = 354) vulden patiënt-gerapporteerde uitkomstmaten in over gezondheids-gerelateerde kwaliteit van leven, hoofd-halskankersymptomen (waaronder vragen over seksuele interesse en seksueel plezier), en angst en depressie. Dit werd gedaan bij elk bezoek aan de polikliniek, van vóór de behandeling tot 24 maanden na afronding van de behandeling. Verminderde seksualiteit (d.w.z. verminderde seksuele interesse en seksueel plezier) werd vaak vermeld: 37% van de patiënten rapporteerde verminderde seksualiteit vóór de behandeling. Bij 6 weken na de behandeling nam dit toe tot 60%. Vanaf 1 jaar na de behandeling en verder keerde seksualiteit terug naar basiswaarden. Oudere leeftijd, problemen met sociaal contact, gewichtsverlies, en constipatie voorafgaand aan de behandeling waren significant geassocieerd met verminderde seksualiteit over de tijd. Vrouwen en patiënten met verminderd sociaal functioneren 6 maanden na behandeling, hadden minder seksualiteit van 6 maanden tot 2 jaar na behandeling. Patiënt-gerapporteerde uitkomstmaten inzetten in de klinische praktijk, kan bijdragen aan de identificatie van patiënten die profiteren van ondersteunende zorg over seksualiteit.

Hoofdstuk 5 gaat over een stapsgewijze zorginterventie voor hoofd-halskankerpatiënten gericht op het verminderen van angst en/of depressie. Er werd geanalyseerd of de interventie ook effectief is in het verminderen van problemen met seksuele interesse en seksueel plezier, vergeleken met gebruikelijke zorg. De stapsgewijze zorginterventie bestond uit de volgende 4 stappen: 1) waakzaam afwachten, 2) begeleide zelfhulp via internet of boekje, 3) kortdurende probleemoplossende therapie en 4) gespecialiseerde psychologische interventies en/of medicatie. Patiënten werden doorverwezen naar een volgende stap van de interventie als de angst en/of depressie verhoogd bleven. In totaal had 76.1% van de 134 hoofd-halskankerpatiënten een onvervulde ondersteunende zorgbehoefte voor seksualiteit voorafgaand aan de interventie, en 24.6% had een psychiatrische stoornis (angst of depressie). De stapsgewijze zorginterventie verminderde problemen met seksuele interesse en seksueel plezier op geen enkele vervolgmeting, vergeleken met gebruikelijke zorg. Dit werd niet gemodereerd door een onvervulde ondersteunende zorgbehoefte voor seksualiteit voorafgaand aan de interventie, of door de aanwezigheid van een psychiatrische stoornis. Stapsgewijze zorg voor angst en depressie leidt niet tot een vermindering van problemen met seksuele interesse en seksueel plezier in deze patiënten. De resultaten suggereren dat er interventies nodig zijn die specifiek gericht zijn op seksualiteit, voor hoofd-halskankerpatiënten die seksuele problemen ervaren.

In **hoofdstuk 6** werden het bereik en de effecten van Koester Je Lijf (“My Changed Body”) onderzocht bij hoofd-halskankerpatiënten die waren behandeld met curatieve intentie.

Koester Je Lijf is een schrijfactiviteit gebaseerd op de techniek van expressief schrijven en zelfcompassie. Hoofd-halskankerpatiënten schrijven eerst over een negatieve ervaring gerelateerd aan hun veranderde lichaam, waardoor ze zich slecht voelden over zichzelf. De daaropvolgende aanwijzingen stimuleren patiënten om over deze gebeurtenis te schrijven vanuit het perspectief van zelfcompassie (mild zijn naar zichzelf, mindfulness, en het gevoel van het gemeenschappelijke mens-zijn), en zo hun lichaamsbeeld te verbeteren. Het bereik van de interventie lag tussen de 15-33% en was significant geassocieerd met een lager opleidingsniveau, problemen met eten in gezelschap en minder problemen met wondgenezing. Er werd geen effect gevonden in de mate van een verstoord lichaamsbeeld, maar zelfcompassie verbeterde significant tot één maand na gebruik van de interventie. Er werden geen factoren gevonden die waren geassocieerd met een verlaagd niveau van verstoord lichaamsbeeld. Gebruikers beoordeelden Koester Je Lijf met het cijfer 7.2 op een schaal van 0-10. Deze pilotstudie toont aan dat Koester Je Lijf tot een derde van de hoofd-halskankerpatiënten bereikt, en dat de interventie effectief lijkt in het bevorderen van zelfcompassie.

Hoofdstuk 7 omvat de algemene discussie van dit proefschrift. Allereerst worden de belangrijkste bevindingen beschreven en in perspectief geplaatst met de bestaande literatuur over lichaamsbeeld en seksualiteit bij hoofd-halskankerpatiënten. Vervolgens worden de bevindingen bediscussieerd aan de hand van een aangepaste versie van het conceptuele model van Rhoten en collega's. In dit aangepaste model beïnvloeden lichaamsbeeld en seksualiteit elkaar wederzijds. De associaties met psychologische distress, patiëntkarakteristieken en sociale factoren worden verhelderd. Ook wordt aangenomen dat problemen met lichaamsbeeld en seksualiteit gedurende het gehele traject van kanker aanwezig kunnen zijn, vanaf de diagnose tot na de behandeling. Hierna komen de pluspunten en beperkingen van de onderzoeken in dit proefschrift aan de orde. Implicaties voor de klinische praktijk en aanbevelingen voor toekomstig onderzoek worden besproken. Dit omvat het regelmatig screenen op lichaamsbeeld en seksualiteit, en meer onderzoek naar effectieve interventies die problemen hierover kunnen verminderen. Het hoofdstuk eindigt met de conclusie dat lichaamsbeeld en seksualiteit cruciale thema's zijn voor een groot aantal hoofd-halskankerpatiënten. Dit proefschrift geeft richting aan adequate screening en ondersteunende zorginterventies om problemen met lichaamsbeeld en seksualiteit te identificeren en de zorg voor hoofd-halskankerpatiënten te verbeteren.

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ABOUT THE AUTHOR

Helena Catharina Melissant was born on September 4th,1989 in Velsen, the Netherlands. In 2007 she completed her secondary education (gymnasium) at Het Noordik, in Almelo. Subsequently, she studied psychology at University of Twente in Enschede. After receiving her bachelor's degree in 2010, Heleen received her master's degree in Health Psychology in 2012. After her graduation she worked as a junior researcher at University of Twente on a study about shared decision making for anti-rheumatic medication. From 2013-2019, she worked for the research group "Living together with cancer" (chair prof. dr. I.M. Verdonck-de Leeuw) as project coordinator for eHealth instrument "Oncokompas" at VU University in Amsterdam and for NET-QUBIC at Amsterdam UMC, location VUmc. She combined this with her PhD-project on body image and sexuality in head and neck cancer patients. During her PhD-project, she visited Macquarie University in Sydney, Australia for a collaboration project on body image. Heleen now works as a psychology teacher at the University of Applied Sciences Leiden and as a nursing teacher at the University of Applied Sciences Amsterdam.

LIST OF PUBLICATIONS

Publications included in this thesis

Melissant HC, Jansen F, Eerenstein SEJ, Cuijpers P, Lissenberg-Witte BI, Sherman KA, Laan E, Leemans CR, Verdonck-de Leeuw IM. A structured expressive writing activity targeting body image distress among head and neck cancer patients: who do we reach and what are the effects? Submitted.

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