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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. Vital functions can be affected, such as breathing, speaking and swallowing. These functional impairments may negatively influence a patient’s body image. Also, appearance changes in the visible head and neck area may influence body image. Surgical treatment may cause scarring, an amputated facial area, an affected facial contour and expression, or result in a tracheostomy. Radiotherapy may induce swelling, fibrosis and alterations in skin pigmentation.

Body image is defined by thoughts, feelings and perceptions about the body and its functions. A previous review identified nine studies that reported the prevalence of body image distress among HNC patients, with prevalence rates ranging from 25-77%. The lowest prevalence was found amongst patients after treatment of oral or oropharyngeal cancer and the highest amongst newly diagnosed oral cancer patients. 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. In addition, it may affect their identity and social relationships. Body image distress may also be related to sexual problems, for example, because HNC patients no longer feel sexually attractive.

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. Patients seem to gradually learn to cope with these situations. 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. 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 that uses theories of expressive writing and self-compassion. 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\(^1\). 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\(^2\) and is translated and validated in Dutch\(^2\).

HRQOL was measured with the EORTC QLQ-C30, a cancer-specific quality of life questionnaire\(^3\), and HNC symptoms were measured using the EORTC QLQ-HN43, a module specifically designed for HNC patients\(^4\). Sexuality was measured with the 6-item Female Sexual Function Index (FSFI-6)\(^5\) for women and 5-item International Index of Erectile Function (IIEF-5)\(^6\) 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\(^7,8\) 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\(^9\). 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)\(^10\). All instruments used in this study are validated\(^11,12,13,14\).

**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\(^1\) and ≥ 8\(^2\). 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\(^3\), 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\(^14\)), 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). 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.

| Characteristics                  | Total sample (n = 233) | Qualitative sample (n = 40) |
|----------------------------------|------------------------|----------------------------|
| 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                              | Total sample (n = 233) | Qualitative sample (n = 40) |
|----------------------------------------------|------------------------|-----------------------------|
| 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 CO2-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

* n = 29 had relevant quotes about their changed body

* 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.

* Only those patients who had a surgical treatment

* Small: CO2-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.

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

| Topic                  | Key issues                                                                 |
|------------------------|-----------------------------------------------------------------------------|
| 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                                           |
| Psychological functioning | Non-visible changes: Changes are invisible from the outside               |
|                        | 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)      |
| Daily functioning      | Feeling bad and ugly: Praying to die right after surgery                  |
|                        | 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  
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 interview⁹. 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 found²⁷,³⁸. In a study among HNC patients for instance <15% had a BIS score higher than 9²⁷, and in a study among female HNC patients the mean overall BIS score was 4.50³⁸.

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 patients⁵. 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 variance⁹. 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.⁹⁰ 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.\textsuperscript{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\textsuperscript{9} and HNC patients from diagnosis until 12 weeks post-treatment\textsuperscript{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\textsuperscript{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\textsuperscript{40}. Over time, HNC patients are at risk to become socially isolated if no active coping strategies are undertaken\textsuperscript{41}. HNC patients who have speech and eating problems report highest levels of social avoidance\textsuperscript{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’\textsuperscript{42}. The other mentioned identity threat was being rejected as a blood donor. Belonging to a social group is important for identity\textsuperscript{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\textsuperscript{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\textsuperscript{36}. Previous studies among HNC patients have reported conflicting results\textsuperscript{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, 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 *              |                | 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 *                         |                | 0.934                |         |
| Negative                      | 1              |                      |         |
| Positive                      | 1.07 [0.24-4.66] |                      |         |
**Prevalence of Body Image Distress in HNC Patients**

| Variable                        | Mean (SD) | OR [95% CI]   | P-value |
|---------------------------------|-----------|---------------|---------|
| EORTC QLQ-C30 summary score     | 84 (14)   | 0.45 [0.34-0.59] | <0.001 |
| EORTC QLQ-HN43                  |           |               |         |
| 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                 |
| 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?                    | 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.
