Body image and sexuality in head and neck cancer patients
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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. 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. 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?” 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; 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). 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 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. 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 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) and the fear-avoidance framework of psychosocial difficulties (fear is likely to lessen with continuing exposure and to increase with avoidance). 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. 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.
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\textsuperscript{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\textsuperscript{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. 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. 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. 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. 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. 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 sexologist 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. Hoole and colleagues 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\textsuperscript{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\textsuperscript{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\textsuperscript{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\textsuperscript{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\textsuperscript{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. Furthermore, the presence of a comorbid disease might influence sexuality as well as body image outcomes. 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. 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”\(^3\). 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 and the International Index for Erectile Function (IIEF) in men. 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. 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, or the intake of medication. A second suggestion is to investigate cultural and relational factors that might be associated with sexuality in HNC patients. 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. 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.

**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.
REFERENCES


