Body image and sexuality in head and neck cancer patients
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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 (α = 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.