

Sexuality and intimacy after head and neck cancer treatment: An explorative prospective pilot study

Jeroen Regeer^{1,A–F}, Paul Enzlin^{2,A–F}, Sofia Prekatsounaki^{2,C–F}, Frédéric Van Der Cruyssen^{1,A–F}, Constantinus Politis^{1,A–F}, Jakob Titiaan Dormaar^{1,A–F}

¹ Department of Oral and Maxillofacial Surgery, University Hospitals Leuven, Belgium

² Institute for Family and Sexuality Studies, Department of Neurosciences, KU Leuven, Belgium

A – research concept and design; B – collection and/or assembly of data; C – data analysis and interpretation;

D – writing the article; E – critical revision of the article; F – final approval of the article

Dental and Medical Problems, ISSN 1644-387X (print), ISSN 2300-9020 (online)

Dent Med Probl. 2022;59(3):323–332

Address for correspondence

Jeroen Regeer

E-mail: jeroenregeer@gmail.com

Funding sources

None declared

Conflict of interest

None declared

Acknowledgements

None declared

Received on January 27, 2022

Reviewed on February 5, 2022

Accepted on April 8, 2022

Published online on September 5, 2022

Abstract

Background. While sexuality and intimacy are suggested to contribute to quality of life (QoL), it is striking that the sexual problems of head and neck cancer patients have not been adequately studied.

Objectives. Our aim was to prospectively assess the impact of head and neck cancer and its treatment on sexuality and intimacy.

Material and methods. A questionnaire study with a 6-month follow-up period was conducted at the University Hospitals Leuven, Belgium, using the Maudsley marital questionnaire (MMQ), the sexual adjustment questionnaire (SAQ) and the short sexual functioning scale (SSFS) to prospectively assess the impact of head and neck cancer and its treatment on sexuality and intimacy.

Results. Twelve patients (67%) reported a negative impact on their sexuality and/or intimacy. There were significant declines in marital, sexual and general life satisfaction ($p < 0.000$) at the 6-month follow-up as compared to baseline. There was a significant increase in frustration after sexual activity ($p = 0.031$). Sexual desire was also impacted, with a near doubling of patients reporting a decline. The perceived importance of discussing sexual issues with one's physician significantly increased from 7 to 16 patients ($p = 0.004$).

Conclusions. Sexual problems are common after head and neck cancer treatment. Using a screening instrument can help to identify patients that need intervention. Discussing sexuality and intimacy issues that patients may face before, during and after treatment can have a positive impact on QoL.

Keywords: sexual dysfunction, sexuality, intimacy, head and neck cancer

Cite as

Regeer J, Enzlin P, Prekatsounaki S, Van Der Cruyssen F, Politis C, Dormaar JT. Sexuality and intimacy after head and neck cancer treatment: An explorative prospective pilot study. *Dent Med Probl.* 2022;59(3):323–332. doi:10.17219/dmp/148156

DOI

10.17219/dmp/148156

Copyright

Copyright by Author(s)

This is an article distributed under the terms of the

Creative Commons Attribution 3.0 Unported License (CC BY 3.0)

(<https://creativecommons.org/licenses/by/3.0/>).

Introduction

Head and neck cancer accounts for approx. 2% of all cancers in Europe.¹ As head and neck cancer is characterized by slow progression and insidious symptoms, patients are often diagnosed at a late stage (III or IV).^{2,3} This leads to greater disease severity at diagnosis, and increased treatment complexity and morbidity. Patients with head and neck cancer have a poor prognosis, with current 5-year survival rates ranging from 35% for oral tumors to 60% for larynx tumors.⁴ The aforementioned late diagnosis combined with the currently available invasive treatment options, i.e., surgery and radiotherapy with or without chemotherapy, result in the disease itself and its treatment having a significant impact on patients' quality of life (QoL). To ensure optimal QoL, an early diagnosis and strict follow-up consultations are essential. An early diagnosis is often facilitated by a well-trained dentist or general practitioner. Non-invasive, radiation-free imaging, such as ultrasound, can be a valuable tool in primary care to identify malignancies at an early stage.⁵ Patients with suspect lesions can be promptly referred to a maxillofacial or head and neck surgeon. Additionally, magnetic resonance imaging (MRI) can be conducted. It is the gold standard, radiation-free imaging technique for soft tissue tumors.⁶

In the follow-up of head and neck cancer patients, several questionnaires, including the European Organization for Research and Treatment of Cancer quality of life questionnaire – head and neck (EORTC QLQ-H&N35) and the University of Washington quality of life questionnaire (UW-QOL), are often used to measure the QoL of patients. As these questionnaires focus mainly on pain, dysphagia, mucositis, xerostomia, appearance, and speech and chewing capabilities, other important determinants of QoL, such as sexuality and intimacy, are mostly not addressed.⁷ This is striking, as the head and neck region is important with regard to appearance, communication with one's partner and kissing, which are vital aspects in the domain of sexuality and intimacy.

The impact of a cancer diagnosis is often felt also by partners, families and in a broader social context.⁸ Many patients experience feelings of anger, anxiety, guilt, depression, hopelessness, and fear of having to depend on others.⁹ Complex treatment, which is necessary, can lead to disfigurement and the loss of function.¹⁰ The direct and indirect physiological and psychological effects of cancer may alter sexual functioning and sexual experience. The partner's preoccupation with managing a cancer patient's care and frequent hospital visits can result in less sexual activity in the relationship.¹¹ Pain and fatigue, before and/or after treatment, can further exacerbate sexual disinterest. Cancer itself may lead to sexual dysfunction, but most problems are attributed to the treatment used, i.e., surgery, radiotherapy and chemotherapy.¹²

Most of the literature pertaining to sexuality and intimacy in cancer patients focuses on gynecological and urological malignancies. Half of these patients report severe sexual dysfunction, including decreased desire, arousal and lubrication, orgasmic concerns, dyspareunia, and erectile dysfunction.¹³ It is worth noting that sexuality and intimacy are a concern for most patients, regardless of age.¹⁴ Due to the prevalence of sexual dysfunction in prostate and gynecological cancer patients, the need to provide information and counseling about such issues has already been recognized for these patient groups. A specific expanded prostate cancer index composite (EPIC) questionnaire has been created to diagnose patients with sexual dysfunction, to assess the degree of sexual dysfunction and to create a treatment plan.¹⁵

In head and neck cancer care, the information and counseling regarding sexuality and intimacy given before, during or after treatment remain limited. Moreover, studies regarding the sexuality of head and neck cancer patients are scarce. A retrospective study specifically evaluating sexual dysfunction in head and neck cancer patients, using a modified version of the sexual adjustment questionnaire (SAQ) was conducted in Cincinnati, USA, from 2008 to 2009.¹⁶ In that study, 42 patients were interviewed 4 months after treatment; all of them reported a negative impact on their sexual relationships due to head and neck cancer, of whom 50% reported an extremely negative impact. Those who underwent surgical treatment were more sexually satisfied as compared to those who were treated with radiotherapy and/or chemotherapy.¹⁶ Researchers in Norway and Sweden examined the QoL of 357 head and neck cancer patients using EORTC QLQ-H&N35 at baseline and at 1, 2, 3, 6, and 12 months after treatment (surgery, radiotherapy, chemotherapy).¹⁷ The aim of that study was to assess what problems the patients faced and for how long. Among other things, the patients reported a significant reduction in sexual function. Unlike in the case of many other problems, e.g., pain, the loss of appetite and fatigue, some of the sexual problems reported by the patients persisted from baseline to the 12-month assessment time point.¹⁷

Currently, most patients with head and neck cancer are middle-aged men. In 1983, a causal relationship was identified between the human papillomavirus (HPV), which is usually contracted during puberty, and oropharyngeal squamous cell carcinoma (SCC).¹⁸ It has been related to a shift in the age of head and neck cancer patients. Younger patients have to cope with long-term treatment side effects for an extended period of time. Head and neck cancer treatment induces specific physiological, psychological, communicational, and relational changes that can affect a patient's ability to be intimate with their partner. Surgery can lead to disfigurement, scarring, changed facial expressions,

altered innervation, and diminished speaking, chewing and swallowing capabilities. Due to advances in technology, the side effects of radiotherapy have been significantly reduced by the use of intensity-modulated radiotherapy (IMRT). However, mucositis, xerostomia and osteonecrosis of the jaw remain considerable side effects. Chemotherapy can cause acute side effects, such as nausea, vomiting and fatigue, which can affect patients' sexual desire and sexual functioning.^{4,19}

Therefore, the aim of the current study was to estimate the prevalence of problems related to sexuality and intimacy after head and neck cancer treatment. We expect that a majority of head and neck cancer patients experience intimacy problems due to treatment-related side effects. Moreover, this study aimed to determine which patients would benefit from additional information and could potentially be helped by referral to a sexologist. Very few prospective studies focusing on sexuality and intimacy within this specific patient population have been conducted.

Material and methods

Study design

The current research consisted of a survey study, including the questionnaires assessing patient sexual functioning (an adapted version of the short sexual functioning scale (SSFS) and an adapted version of SAQ), and marital and sexual satisfaction (the Maudsley marital questionnaire (MMQ)). The inclusion criteria were as follows: adults aged 18 years and above; and a primary head and neck cancer diagnosis (i.e., oral cavity, pharynx, larynx, paranasal sinuses, salivary glands, thyroid gland, or unknown primary) from September 2016 to January 2017 at the University Hospitals Leuven, Belgium. The cancers included T1–4, N0–3, M0 disease, mostly histologically confirmed SCC, but other histological types were also eligible. The patients were recruited from the departments of maxillofacial surgery, otorhinolaryngology

and radiotherapy-oncology. The patients needed to be available to attend a long-term follow-up. The following exclusion criteria were applied: patients with recurrent head and neck cancer that was already treated with surgery, radiotherapy and/or chemotherapy; patients diagnosed with depression according to the “Diagnostic and Statistical Manual of Mental Disorders: DSM-5™” (5th ed.) criteria²⁰; patients with cognitive impairment that resulted in an inability to complete the questionnaires; and patients with previous or concurrent illnesses that could interfere with follow-up (Table 1). The respondents were interviewed the day before their initial treatment (surgery, radiotherapy and/or chemotherapy). Pre-treatment sexual assessment screening is essential because of varying baseline (pre-existing) sexual functioning and satisfaction among patients. Six months after the completion of treatment, the respondents were asked to complete the questionnaires again to evaluate changes as compared to the baseline scores. The study protocol and procedure were approved by the Ethics Committee at the University Hospitals Leuven (No. of approval: S-59565).

Patient characteristics

The patient characteristics are presented in Table 2. In total, 45 head and neck cancer patients were reviewed for inclusion, of whom 26 had a new diagnosis. Of these 26 patients, 7 declined (1 man and 6 women). In total, 19 men completed the questionnaires before treatment, of whom 18 (mean age: 62.1 years) also completed the questionnaires at the follow-up 6 months post-treatment. One patient died within the 6-month follow-up period. At baseline, 15 patients (83%) reported having a partner; one patient's partner passed away between the baseline and follow-up questioning. While almost all participants ($n = 16$; 89%) reported a history of smoking (mean pack years: 31.3), 6 patients (33%) were still active smokers during the study period. Fourteen patients (78%) reported daily alcohol consumption and 6 patients (33%) had a history of alcohol abuse.

Table 1. Patient inclusion and exclusion criteria

| Criteria | Description |
|--------------------|---|
| Inclusion criteria | <ul style="list-style-type: none"> – age 18 years and above – primary head and neck cancer diagnosis (i.e., oral cavity, pharynx, larynx, paranasal sinuses, salivary glands, thyroid gland, or unknown primary) – T1–4, N0–3, M0 disease, mostly histologically confirmed SCC, but other histological types were also eligible – available to attend a long-term follow-up |
| Exclusion criteria | <ul style="list-style-type: none"> – recurrent head and neck cancer that was already treated with surgery, radiotherapy and/or chemotherapy – depression according to the “Diagnostic and Statistical Manual of Mental Disorders: DSM-5” (5th ed.) criteria – cognitive impairment with an inability to complete the questionnaires – previous or concurrent illness that could interfere with follow-up |

SCC – squamous cell carcinoma.

Table 2. Patient characteristics

| Patient | Age [years] | Gender | Cancer site | Stage* | Partner | Current smoker | History of smoking |
|---------|-------------|--------|--------------------|--------|---------|----------------|--------------------|
| 1 | 56 | male | unknown primary | IVA | no | yes | yes |
| 2 | 59 | male | larynx/hypopharynx | IVA | yes | no | yes |
| 3 | 56 | male | oropharynx | IVA | yes | no | no |
| 4 | 82 | male | larynx/hypopharynx | II | yes | yes | yes |
| 5 | 73 | male | larynx/hypopharynx | IVA | yes | no | yes |
| 6 | 54 | male | oropharynx | IVB | no | yes | yes |
| 7 | 71 | male | oral cavity | IVA | yes | no | yes |
| 8 | 68 | male | salivary gland | II | yes | yes | yes |
| 9 | 58 | male | oral cavity | IVA | yes | no | yes |
| 10 | 61 | male | salivary gland | IVA | yes | no | yes |
| 11 | 61 | male | oral cavity | I | yes | yes | yes |
| 12 | 65 | male | larynx/hypopharynx | IVA | yes | no | yes |
| 13 | 57 | male | thyroid gland | III | no | no | yes |
| 14 | 46 | male | thyroid gland | III | no | no | yes |
| 15 | 54 | male | thyroid gland | IVA | yes | no | yes |
| 16 | 61 | male | oral cavity | IVA | yes | yes | yes |
| 17 | 64 | male | oral cavity | III | yes | no | yes |
| 18 | 73 | male | salivary gland | IVA | yes | no | no |

* The head and neck cancer stage defined according to the American Joint Committee on Cancer (AJCC) tumor, node, metastasis (TNM) classification (Amin MB, Edge S, Greene F, et al., eds. *AJCC Cancer Staging Manual*. 8th ed. New York, NY: Springer International Publishing: American Joint Committee on Cancer; 2017).

Cancer type and treatment

The study population had a variety of head and neck cancer sites, with stages ranging from I to IVB. After a multidisciplinary discussion, each patient received a tailored treatment consisting of surgery, radiotherapy, chemotherapy, or a combination of these.

One patient was diagnosed with stage I oral cavity cancer and underwent a tumorectomy. Of the 2 patients with stage II cancer, one was treated with radiotherapy and the other was treated with surgery (parotidectomy and neck dissection) followed by adjuvant radiotherapy. The 3 patients with stage III cancer were treated surgically, including neck dissections; the 2 patients with thyroid carcinoma also received adjuvant iodotherapy, whereas the third patient (SCC of the tongue) underwent a hemi-glossectomy and reconstruction with a radial forearm free flap (RFFF), and received adjuvant radiotherapy. Twelve patients (67%) were diagnosed with stage IV head and neck cancer. Three were treated with radio-chemotherapy and 9 were treated surgically. Of those treated surgically, all 9 underwent a neck dissection and 6 received reconstructive surgery involving RFFF, a pectoralis major flap (PMF), a fibula free flap (FFF), an anterolateral thigh (ALT) flap, and/or a deep circumflex iliac artery (DCIA) flap. Of these 9 patients, 8 received adjuvant radiotherapy and 1 received adjuvant iodotherapy.

When radiotherapy was indicated, IMRT was used with a total dosage ranging from 60 Gy to 72 Gy (2 Gy per session

for 6 weeks). The most commonly used chemotherapy regimen was cisplatin (100 mg/m²) given intravenously during weeks 2, 4 and 6 of the radiation treatment. All 3 thyroidectomy patients received 100 mCi I-131 (Table 3).

Questionnaires

Partner relationship quality was measured with MMQ.^{21,22} The MMQ is a standardized and validated questionnaire consisting of 20 items relating to marital (MMQ-M), sexual (MMQ-S) and general life satisfaction (MMQ-G), with a 9-point (0–8) scale appended to each question. Scores on MMQ-M range from 0 to 80, and scores on MMQ-S and MMQ-G range from 0 to 40. Higher scores reflect greater dissatisfaction. In this sample, Cronbach's alpha for MMQ was acceptable with 0.74 at baseline, and good with 0.90 at the 6-month follow-up.

Sexual activity was measured with an adapted version of SAQ.^{23–25} The SAQ is a standardized and validated questionnaire used to assess the importance and frequency of sexual activity over time. Measurement is based on a 4–6-point Likert-type scale. Higher scores indicate either a higher perceived importance of sexual activity, ranging from 1 (very unimportant) to 6 (very important), or less frequent sexual activity, ranging from 1 (in the hospital) to 6 (not yet).

Sexual difficulties and sexual distress due to sexual difficulties were measured by means of an adapted version of SSFS.²⁶

Table 3. Head and neck cancer treatment received by each patient

| Patient | Age [years] | Gender | Treatment | Type | Adjuvant treatment | Type |
|---------|-------------|--------|--------------------|---|--------------------|---------------------|
| 1 | 56 | male | surgery | tonsillectomy bilateral + SOND (zone I–III) left | radio-chemotherapy | 60 Gy + cisplatinum |
| 2 | 59 | male | radio-chemotherapy | 72 Gy + cisplatinum | none | – |
| 3 | 56 | male | radio-chemotherapy | 70 Gy + cisplatinum | none | – |
| 4 | 82 | male | radiotherapy | 70 Gy | none | – |
| 5 | 73 | male | surgery | total laryngectomy and total thyroidectomy + MRND (zone II–V) left + PMF right | radiotherapy | 60 Gy |
| 6 | 54 | male | radio-chemotherapy | 72 Gy + cisplatinum | none | – |
| 7 | 71 | male | surgery | tumorectomy with mandibular continuity resection en bloc + SOND (zone I–III) bilateral + FFF | radiotherapy | 60 Gy |
| 8 | 68 | male | surgery | total parotidectomy left + SOND (zone II–III) left | radiotherapy | 60 Gy |
| 9 | 58 | male | surgery | tumorectomy left + MRND (zone I–V) right and MRND (zone I–III) left + ALT flap left | radiotherapy | 60 Gy |
| 10 | 61 | male | surgery | tonsillectomy and tongue base right + MRND (zone I–V) right | radiotherapy | 60 Gy |
| 11 | 61 | male | surgery | tumorectomy left | none | – |
| 12 | 65 | male | surgery | total laryngectomy + MRND (zone II–V) right and selective neck dissection (zone III–IV) left + PMF right | radiotherapy | 60 Gy |
| 13 | 57 | male | surgery | total thyroidectomy + central neck dissection (zone VI–VII) bilateral and selective neck dissection (zone II–V) right | iodotherapy | 100 mCi I-131 |
| 14 | 46 | male | surgery | total thyroidectomy + central neck dissection (zone VI–VII) bilateral and selective neck dissection (zone II–IV) left | iodotherapy | 100 mCi I-131 |
| 15 | 54 | male | surgery | total thyroidectomy + central neck dissection (zone VI–VII) bilateral and MRND (zone I–V) left | iodotherapy | 100 mCi I-131 |
| 16 | 61 | male | surgery | tumorectomy right with mandibular continuity resection en bloc + MRND (zone I–V) right + DCIA flap and ALT flap right | radiotherapy | 60 Gy |
| 17 | 64 | male | surgery | hemi-glossectomy left + MRND (zone I–V) left + RFFF left | radio-chemotherapy | 60 Gy + cisplatinum |
| 18 | 73 | male | surgery | total parotidectomy left + MRND (zone I–V) left + RFFF left | radiotherapy | 66 Gy |

SOND – supraomohyoid neck dissection; MRND – modified radical neck dissection; PMF – pectoralis major flap; FFF – fibula free flap; ALT – anterolateral thigh; DCIA – deep circumflex iliac artery; RFFF – radial forearm free flap.

The SSFS focuses on whether and to what extent patients experienced a range of impairments in sexual functioning during the past 6 months. The impairments addressed by SSFS are a lack of sexual desire (hypoactive sexual desire), erectile difficulties, and absent or delayed orgasm. Impairments in sexual functioning are rated on a 4-point Likert scale (1 – no; 2 – slight; 3 – moderate; and 4 – severe or extreme). A sexual difficulty was considered present only when the participants reported at least a moderate impairment in sexual functioning. In addition, the respondents were asked to evaluate how distressing each sexual difficulty was for them (personal sexual distress). The severity of distress was scored on a 3-point Likert scale (1 – no or mild distress; 2 – moderate distress; and 3 – severe or extreme distress). If the respondents had a score of at least 2, then distress was considered present. Respondents with a sexual difficulty and associated personal sexual distress were considered to have sexual dysfunction.

Finally, the questionnaire contained 2 questions to measure the necessity to discuss sexual problems and issues with their partner and/or a healthcare professional. Comparing the baseline and 6-month follow-up results enabled us to identify sexual issues that patients may encounter during and after treatment.

Statistical analysis

The data was analyzed using the IBM SPSS Statistics for Windows software, v. 25.0 (IBM Corp., Armonk, USA). Paired *t* tests were conducted to compare the participants' scores regarding partner relationship quality at baseline and at the 6-month follow-up. The comparison of the participants' sexual activity and sexual functioning at the same measurement time points was done using McNemar's tests. The significance level for all analyses was set at $p < 0.05$.

Results

In total, 12 patients (67%) reported a negative impact on their sexuality and/or intimacy, which means that they reported at least 1 sexual difficulty or sexual dysfunction after their head and neck cancer treatment.

Partner relationship quality

The mean scores on MMQ for the 14 patients with a partner declined significantly between baseline (31.93 ±14.31) and the follow-up (51.21 ±17.85) ($t = -7.72$; $p < 0.000$). In addition to this decline in the patients' total scores, a significant decline between baseline and the follow-up was also found in the average scores on all subscales of MMQ (MMQ-M: $t = -8.21$, $p < 0.000$; MMQ-S: $t = -3.42$, $p = 0.005$; MMQ-G: $t = -5.41$, $p < 0.000$) (Table 4).

Table 4. Partner relationship quality scores (baseline vs. follow-up) using the Maudsley marital questionnaire (MMQ)

| MMQ scale/subscale | Baseline | Follow-up | Paired <i>t</i> tests | |
|--------------------|--------------|--------------|-----------------------|-----------------|
| | | | <i>t</i> | <i>p</i> -value |
| MMQ-M | 9.21 ±5.35 | 17.93 ±6.83 | -8.21 | 0.000* |
| MMQ-S | 15.57 ±11.34 | 20.07 ±8.17 | -3.42 | 0.005* |
| MMQ-G | 7.14 ±4.67 | 13.21 ±7.10 | -5.41 | 0.000* |
| MMQ-total | 31.93 ±14.31 | 51.21 ±17.85 | -7.72 | 0.000* |

Data presented as mean ± standard deviation ($M \pm SD$). $N = 14$; MMQ-M – marital component; MMQ-S – sexual component; MMQ-G – general life component; *statistically significant.

Sexual activity

Thirteen patients reported to be sexually active at baseline and 14 reported sexual activity at the 6-month follow-up. While 1 patient regained sexual activity within 1 month after the completion of treatment and 1 patient after 3–6 months, most patients ($n = 12$) restarted solo sexual activity within 1–3 months. Most patients ($n = 11$) resumed partnered sexual activity within 1–3 months, while 3 of them had not resumed sexual activity with a partner after treatment at the time of the 6-month follow-up. As the results in Table 5 show, most participants found sexual activity ($n = 9$), kissing ($n = 10$) and French kissing ($n = 7$) important at baseline. Their reports on the importance of these activities at the 6-month follow-up were not significantly different. The number of participants that reported feeling frustration after sexual activity was significantly increased at the follow-up ($n = 12$) as compared to baseline ($n = 6$) ($p = 0.031$).

After treatment, 13 patients reported difficulties with kissing, 7 of whom reported mild difficulties, whereas 6 reported severe difficulties. Of these 6 patients, 3 received radiotherapy and 2 radio-chemotherapy (either

as primary or adjuvant treatment), while 1 patient was only treated surgically. The issues encountered included pain, xerostomy, mucositis, and decreased tongue mobility.

Table 5. Sexual activity scores (baseline vs. follow-up) using the sexual adjustment questionnaire (SAQ)

| Category | Paired <i>N</i> | Baseline | Follow-up | McNemar's tests <i>p</i> -value |
|---------------------------|-----------------|----------|-----------|---------------------------------|
| Sexually active | 18 | 13 (72) | 14 (78) | 1.000 |
| Sexual activity important | 13 | 9 (69) | 10 (77) | 1.000 |
| Kissing important | 13 | 10 (77) | 11 (85) | 1.000 |
| French kissing important | 12 | 7 (58) | 7 (58) | 1.000 |
| Sexually frustrated | 13 | 6 (46) | 12 (92) | 0.031* |

Data presented as number (percentage) (n (%)). * statistically significant. Note: Paired *N*'s differ between variables, as McNemar's test requires that each participant filled out the pre- and post-measurement questionnaires.

Sexual functioning

At baseline, 5 patients reported problems with sexual desire. This number raised to 9 at the 6-month follow-up, although the increase was not statistically significant ($p = 0.125$) (Table 6). Of the patients with sexual desire difficulties, 3 patients at baseline and 8 patients at the follow-up reported personal distress related to their sexual difficulty, meeting the criteria for sexual dysfunction. Finally, the reports of partner distress increased from 4 to 11 between baseline and the follow-up, while the relationship distress resulting from their low sexual desire was reported by 3 patients at baseline and 12 patients at the follow-up. At the follow-up, 3 of these patients reported an extreme loss of sexual desire, 1 of whom was an 82-year-old patient and another had been previously treated for prostate cancer.

At baseline, 4 patients reported erectile difficulties, 3 of whom experienced associated personal distress. The number of patients reporting erectile difficulties ($n = 6$) and dysfunction ($n = 5$) slightly increased at the 6-month follow-up. At baseline, 2 patients reported partner distress related to the patients' erectile difficulties and 3 patients rated their erectile difficulties as distressing for their relationship. At the 6-month follow-up, the number of patients reporting partner and relationship distress increased to 9.

In total, 6 patients indicated difficulties in achieving orgasm at baseline and the same participants reported orgasm difficulties at the follow-up. Three patients noted extreme difficulties; 1 of them had undergone a radical prostatectomy in the past and another was treated with radio-chemotherapy for a larynx tumor. All 6 patients reported personal distress at baseline as well as at the 6-month follow-up. Additionally, 3 patients considered their orgasm difficulties as distressing for their partner and their relationship at baseline, and the reports

of partner ($n = 7$) and relationship ($n = 8$) distress increased at the 6-month follow-up.

One patient at baseline and 2 patients at the follow-up reported that they achieved orgasm too fast (premature ejaculation). In all cases, premature ejaculation was accompanied by personal distress, although partner distress at baseline ($n = 2$) and at the follow-up ($n = 3$), as well as relationship distress at both measurement points ($n = 3$), were even more frequently reported.

Only 1 patient, the oldest one participating in the study, reported that sexual intercourse was impossible at baseline. At the 6-month follow-up, 1 additional patient reported that vaginal penetration was not possible anymore (Table 6).

Table 6. Scores for sexual difficulties (baseline vs. follow-up) using the short sexual functioning scale (SSFS)

| Category | Paired <i>N</i> | Baseline | Follow-up | McNemar's tests <i>p</i> -value |
|-----------------------|-----------------|----------|-----------|------------------------------------|
| Desire | 18 | 5 (28) | 9 (50) | 0.125 |
| Responsive desire | 16 | 3 (19) | 6 (38) | 0.250 |
| Erection | 16 | 4 (25) | 6 (37) | 0.500 |
| Orgasm | 16 | 6 (38) | 6 (38) | 1.000 |
| Premature ejaculation | 15 | 1 (7) | 2 (13) | 1.000 |
| Penetration | 15 | 1 (7) | 2 (13) | 1.000 |

Data presented as n (%).

Note: Paired *N*'s differ between variables, as McNemar's test requires that each participant filled out the pre- and post-measurement questionnaires.

Discussing sexuality and intimacy

The last 2 questions of the questionnaire aimed to explore the importance of discussing sexuality and intimacy with one's partner and/or a healthcare professional (Table 7). At baseline, 9 out of 16 patients believed it was important to discuss sexual issues with the partner. At the 6-month follow-up, this number increased to 13 patients. At baseline, 7 patients thought it was important that healthcare professionals discussed sexuality and intimacy with head and neck cancer patients. At the 6-month follow-up, this number significantly increased to 16 patients reporting that explaining the sexual implications of head and neck cancer treatment by the doctor was valuable ($p = 0.004$).

Table 7. Discussing sexuality and intimacy with the partner and/or a healthcare professional (baseline vs. follow-up)

| Category | Paired <i>N</i> | Baseline | Follow-up | McNemar's tests <i>p</i> -value |
|---|-----------------|----------|-----------|------------------------------------|
| Important to discuss with the partner | 16 | 9 (56) | 13 (81) | 0.125 |
| Important to discuss with a healthcare professional | 18 | 7 (39) | 16 (89) | 0.004* |

Data presented as n (%). * statistically significant.

Note: Paired *N*'s differ between variables, as McNemar's test requires that each participant filled out the pre- and post-measurement questionnaires.

Discussion

Prospective study

The current study is an explorative prospective pilot study specifically focusing on sexuality in the context of QoL after head and neck cancer treatment. Most head and neck cancer QoL studies use validated questionnaires, such as EORTC QLQ-H&N35.⁷ These instruments are good for evaluating global QoL, i.e., pain, speech, chewing, taste, mood, and anxiety, but with only 1 or 2 questions about sexuality, they are inadequate for analyzing sexual QoL. In order to cover that part of QoL, a questionnaire combining MMQ, SAQ and SSFS was used to assess sexuality and intimacy before and after head and neck cancer treatment. The importance of a high-quality questionnaire with multidisciplinary input cannot be underestimated. By having patients fill out a baseline questionnaire at the time of diagnosis, but before treatment, we were able to make a good comparison with the sexuality issues reported at the time of the 6-month follow-up interview.

Head and neck cancer and its treatment may have a profound effect on sexuality and intimacy, and changes in sexual functioning and the relationship with one's partner can significantly influence overall QoL.²⁷ It is worth noting that there is a lack of research pertaining to sexuality and head and neck cancer. Most studies examine overall QoL, without a specific focus on the sexual aspects.^{28,29} The sexual problems and unmet support needs of head and neck cancer patients are often not adequately identified, and until now, no real guidance or treatment options have been studied. The fact that sexual problems tend to persist after a 6-month follow-up period supports the need for better screening and treatment.^{17,30}

The marital, sexual and general life satisfaction MMQ scores significantly declined between baseline and the follow-up, indicating that head and neck cancer and its treatment bring stress into the relationship. It is important to note that the effect size for the marital subscale was greater than for the sexual subscale, meaning that there was a greater decline in relationship satisfaction than in sexual satisfaction. This bigger decline in relational satisfaction may be due to the fact that in the acute phase and during the first months after treatment, patients lose their interest in sexuality and are more focused on relationship satisfaction because of stress due to the diagnosis.

As described in previous studies and as our study suggests, the levels of sexual functioning decrease after the diagnosis and treatment of head and neck cancer.^{31–33} While most patients admitted that sexual activity, even at old age, remains important, kissing problems and sexual frustration were prevalent among the majority of patients after treatment. This is not surprising, considering that head and neck cancer surgery can change one's appearance and ability to kiss. Also, cancer takes a considerable

toll on daily life, especially in the case of patients that undergo radio(chemo)therapy.³⁴ This also became apparent when analyzing the SSFS data, suggesting that erectile dysfunction and the loss of sexual desire may become more prevalent and severe after treatment. A near doubling of patients who reported a decrease in sexual desire after treatment is a striking finding, although without reaching statistical significance. As this finding referred to a small group, it should be further studied in a larger population. Unfortunately, a comparison between patients with different cancer sites or different treatment modalities was difficult to conduct because of the small study population. However, we did notice a trend toward having more sexual problems among patients with oral cavity cancer and/or patients that underwent radio(chemo)therapy. As expected, patients with a higher tumor stage at the time of diagnosis tended to have more sexual problems as well. These results are in line with other studies in the literature.¹⁶

In the case of head and neck cancer there is a male predominance (2.5:1 in Western Europe) due to a higher prevalence of tobacco and alcohol abuse.³⁵ Interestingly, all our study patients were men. We approached 6 women to participate in the study, but unfortunately all declined. This is somewhat unexpected, as women in studies on gynecological cancers seemed quite willing to talk about these types of problems.¹³ Other studies have shown that men tend to be more satisfied with their sexual QoL than women.¹⁶

Interventions for sexuality and intimacy

In our study, it became apparent that at the 6-month follow-up, more patients realized the importance of proper guidance in managing their sexual problems. The management of sexual problems should start even before the treatment begins. Medical specialists are obliged to provide information about a given treatment modality, including its possible complications and side effects, and they should obtain oral informed consent before a therapeutic intervention can be started. It seems that the sexual side effects of treatment are rarely discussed. It is striking that often no information is given regarding this important determinant of QoL.

Discussing sexual issues with the patient before treatment shows that the healthcare provider is aware of their importance, and it may lower the threshold to talk about possible problems in the future. It is also crucial to include the partner in the conversation.

After cancer treatment, the first step toward the optimal way of managing sexual problems is to identify patients at risk for sexual issues. The identification of patients with sexual problems could be done easily by using a screening instrument, such as SSFS. When the patient and their partner are open to therapy, treatment is typically combined with providing adequate information about the sexual side effects of interventions, and can include a combination of strengthening coping strategies, sex therapy,

sexual aids, and sexual experimentation without the need for sexual intercourse. These must be discussed during follow-up consultations and tailored to what patients and their partners need.

Due to the sensitive nature of sexuality and intimacy, some healthcare providers find it difficult to talk about these issues with their patients. Research has shown that patients would prefer that their doctor initiated the discussion. The BETTER model is a mnemonic that can help to facilitate the conversation.³⁶ The acronym BETTER refers to: **B**ring up the topic of sexuality; **E**xplain that it is part of QoL; **T**ell the patient that information will be given; **T**ime the discussion and let the patient know that sexuality can be talked about at any point in time; **E**ducate the patient about the sexual side effects of treatment; and **R**ecord findings in the patient's medical records.³⁷ Specific suggestions that enable patients to improve their sexual functioning or experience (e.g., changing medication, the use of a lubricant or the use of a phosphodiesterase type 5 (PDE-5) inhibitor) are useful. The last step is referring patients with sexual problems to a qualified psychosexual therapist.³⁸

Limitations

As with every questionnaire-based study, the answers given are subjective and represent a snapshot of one particular moment in time. A longer follow-up (12 months) would provide us with even more data and the ability to assess if sexual function recuperates or stabilizes with time.

Our study sample was limited to 18 patients that were gathered from different departments (i.e., maxillofacial surgery, otorhinolaryngology and radiotherapy-oncology) and it proved to be difficult for a single part-time healthcare professional to see patients at the different locations. It is also worth noting that sexuality and intimacy remains a sensitive topic, and that it may still be a big taboo for both patients and medical specialists. The aforementioned issues inherently limited the sample size of the current study.

Conclusions

The current prospective study revealed that a majority of head and neck cancer patients experience sexual problems during and after treatment. The persistence of sexual problems, as shown in our long-term follow-up study, and the fact that patients often do not realize the need for information and guidance until after treatment, makes it essential for healthcare professionals to bring up the topic of sexuality before treatment and during follow-up consultations. Effective intervention techniques for sexual problems start with the identification of patients with sexual problems by using a screening

instrument and discussing a treatment plan. However, more research must be conducted to find out how to effectively implement specific sexual intervention programs in head and cancer treatment centers. Only by bringing together the knowledge of head and neck cancer specialists and the expertise of a qualified psychosexual therapist will we be able to help patients with the sexual problems they are confronted with.

Ethics approval and consent to participate

The study protocol and procedure were approved by the Ethics Committee at the University Hospitals Leuven, Belgium (No. of approval: S-59565). Written informed consent was obtained from all participants.

Data availability


All data generated and/or analyzed during this study is included in this published article.


Consent for publication


Not applicable.


ORCID iDs


Jeroen Regeer  <https://orcid.org/0000-0002-3113-8884>

Paul Enzlin  <https://orcid.org/0000-0002-6641-5159>

Sofia Prekatsounaki  <https://orcid.org/0000-0001-5996-0434>

Frédéric Van Der Cruyssen  <https://orcid.org/0000-0002-6888-9219>

Constantinus Politis  <https://orcid.org/0000-0003-4772-9897>

Jakob Titiaan Dormaar  <https://orcid.org/0000-0001-9382-2473>

References

1. Ferlay J, Soerjomataram I, Dikshit R, et al. Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer*. 2015;136(5):E359–E386. doi:10.1002/ijc.29210
2. Alho OP, Teppo H, Mäntyselkä P, Kantola S. Head and neck cancer in primary care: Presenting symptoms and the effect of delayed diagnosis of cancer cases. *CMAJ*. 2006;174(6):779–784. doi:10.1503/cmaj.050623
3. Debes Felippu AW, Freire EC, de Arruda Silva R, Guimarães AV, Dedivitis RA. Impact of delay in the diagnosis and treatment of head and neck cancer. *Braz J Otorhinolaryngol*. 2016;82(2):140–143. doi:10.1016/j.bjorl.2015.10.009
4. Henry M, Habib LA, Morrison M, et al. Head and neck cancer patients want us to support them psychologically in the posttreatment period: Survey results. *Palliat Support Care*. 2013;12(6):481–493. doi:10.1017/S1478951513000771
5. Reda R, Zanza A, Cicconetti A, et al. Ultrasound imaging in dentistry: A literature overview. *J Imaging*. 2021;7(11):238. doi:10.3390/jimaging7110238
6. Reda R, Zanza A, Mazzoni A, Cicconetti A, Testarelli L, Di Nardo D. An update of the possible applications of magnetic resonance imaging (MRI) in dentistry: A literature review. *J Imaging*. 2021;7(5):75. doi:10.3390/jimaging7050075
7. Ojo B, Genden EM, Teng MS, Milbury K, Misiukiewicz KJ, Badr H. A systematic review of head and neck cancer quality of life assessment instruments. *Oral Oncol*. 2012;48(10):923–937. doi:10.1016/j.oraloncology.2012.03.025
8. Edwards B, Clarke V. The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psychooncology*. 2004;13(8):562–576. doi:10.1002/pon.773
9. Zabora J, Brintzenhofe-Szoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psychooncology*. 2001;10(1):19–28. doi:10.1002/1099-1611(200101/02)10:1<19::aid-pon501>3.0.co;2-6
10. Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. Psychosocial adjustment in head and neck cancer: The impact of disfigurement, gender and social support. *Head Neck*. 2002;25(2):103–112. doi:10.1002/hed.10174
11. Ofman U. "...And how are things sexually?" Helping patients adjust to sexual changes before, during, and after cancer treatment. *Support Cancer Ther*. 2004;1(4):243–247. doi:10.3816/SCT.2004.n.017
12. Verschuren JE, Enzlin P, Dijkstra PU, Geertzen JH, Dekker R. Chronic disease and sexuality: A generic conceptual framework. *J Sex Res*. 2010;47(2):153–170. doi:10.1080/00224491003658227
13. Sadovsky R, Basson R, Krychman M, et al. Cancer and sexual problems. *J Sex Med*. 2010;7(1):349–373. doi:10.1111/j.1743-6109.2009.01620.x
14. Kalra G, Subramanyam A, Pinto C. Sexuality: Desire, activity and intimacy in the elderly. *Indian J Psychiatry*. 2011;53(4):300–306. doi:10.4103/0019-5545.91902
15. Schover LR, Van der Kaaij M, Van Dorst E, Creutzberg C, Huyghe E, Kiserud CE. Sexual dysfunction and infertility as late effects of cancer treatment. *EJC Suppl*. 2014;12(1):41–53. doi:10.1016/j.ejcsup.2014.03.004
16. Moreno KF, Khabbaz E, Gaitonde K, Meinzen-Derr J, Wilson KM, Patil YJ. Sexuality after treatment of head and neck cancer: Findings based on modification of sexual adjustment questionnaire. *Laryngoscope*. 2012;122(7):1526–1231. doi:10.1002/lary.23347
17. Bjordal K, Ahlner-Elmqvist M, Hammerlid E, et al. A prospective study of quality of life in head and neck cancer patients. Part II: Longitudinal data. *Laryngoscope*. 2001;111(8):1440–1452. doi:10.1097/00005537-200108000-00022
18. Syrjänen K, Syrjänen S, Lamberg M, Pyrhönen S, Nuutinen J. Morphological and immunohistochemical evidence suggesting human papillomavirus (HPV) involvement in oral squamous cell carcinogenesis. *Int J Oral Surg*. 1983;12(6):418–424. doi:10.1016/S0300-9785(83)80033-7
19. Rhoten BA. Head and neck cancer and sexuality: A review of the literature. *Cancer Nurs*. 2016;39(4):313–320. doi:10.1097/NCC.0000000000000289
20. American Psychiatric Association; DSM-5 Task Force. *Diagnostic and Statistical Manual of Mental Disorders: DSM-5™*. 5th ed. Washington, DC: American Psychiatric Publishing, Inc.; 2013. doi:10.1176/appi.books.9780890425596
21. Arrindell WA, Emmelkamp PM, Bast S. The Maudsley marital questionnaire (MMQ): A further step towards its validation. *Pers Individ Dif*. 1983;4(5):457–464. doi:10.1016/0191-8869(83)90075-2
22. Orathinca J, Vansteenwegen A, Stroobants R. Further validation of the Maudsley Marital Questionnaire (MMQ). *Psychol Health Med*. 2007;12(3):346–352. doi:10.1080/13548500600855481
23. Waterhouse J, Metcalfe MC. Development of the sexual adjustment questionnaire. *Oncol Nurs Forum*. 1986;13(3):53–59. PMID:3635138.
24. Wilmoth MC, Hanlon AL, Ng LS, Bruner DW. Factor analysis of the modified Sexual Adjustment Questionnaire – Male. *J Nurs Meas*. 2014;22(2):241–254. doi:10.1891/1061-3749.22.2.241
25. Metcalfe MC. Reliability and validity testing of the sexual adjustment questionnaire. In: Strickland OL, Waltz CF, eds. *Measurement of Nursing Outcomes. Vol. 4: Measuring Client Self-Care and Coping Skills*. New York, NY: Springer; 1990:286–319.
26. Enzlin P, Weyers S, Janssens D, et al. Sexual functioning in women using levonorgestrel-releasing intrauterine systems as compared to copper intrauterine devices. *J Sex Med*. 2012;9(4):1065–1073. doi:10.1111/j.1743-6109.2011.02266.x
27. Grattan K, Kubrak C, Caine V, O'Connell DA, Olson K. Experiences of head and neck cancer patients in middle adulthood: Consequences and coping. *Glob Qual Nurs Res*. 2018;5:2333393618760337. doi:10.1177/2333393618760337
28. Zwahlen RA, Dannemann C, Grätz KW, et al. Quality of life and psychiatric morbidity in patients successfully treated for oral cavity squamous cell cancer and their wives. *J Oral Maxillofac Surg*. 2008;66(6):1125–1132. doi:10.1016/j.joms.2007.09.003
29. Lee Y, Lin PY, Chien CY, Fang FM, Wang LJ. A comparison of psychological well-being and quality of life between spouse and non-spouse caregivers in patients with head and neck cancer: A 6-month follow-up study. *Neuropsychiatr Dis Treat*. 2018;14:1697–1704. doi:10.2147/NDT.S162116

30. Tsai WL, Chien CY, Huang HY, Liao KC, Fang FM. Prognostic value of quality of life measured after treatment on subsequent survival in patients with nasopharyngeal carcinoma. *Qual Life Res.* 2013;22(4):715–723. doi:10.1007/s11136-012-0213-8
31. Hirani I, Siddiqui AH, Khyani IA. Apprehensions and problems after laryngectomy: Patients' perspective. *J Pak Med Assoc.* 2015;65(11):1214–1218. PMID:26564296.
32. Herranz J, Gavilán J. Psychosocial adjustment after laryngeal cancer surgery. *Ann Otol Rhinol Laryngol.* 1999;108(10):990–997. doi:10.1177/000348949910801011
33. Osthus AA, Aarstad AK, Olofsson J, Aarstad HJ. Head and neck specific Health Related Quality of Life scores predict subsequent survival in successfully treated head and neck cancer patients: A prospective cohort study. *Oral Oncol.* 2011;47(10):974–979. doi:10.1016/j.oraloncology.2011.07.010
34. Nguyen NP, Sallah S, Karlsson U, Antoine JE. Combined chemotherapy and radiation therapy for head and neck malignancies: Quality of life issues. *Cancer.* 2002;94(4):1131–1141. doi:10.1002/cncr.10257
35. Torre LA, Bray F, Siegel RL, Ferlay J, Lortet-Tieulent J, Jemal A. Global cancer statistics, 2012. *CA Cancer J Clin.* 2015;65:87–108. doi:10.3322/caac.21262
36. Stabile C, Goldfarb S, Baser RE, et al. Sexual health needs and educational intervention preferences for women with cancer. *Breast Cancer Res Treat.* 2017;165(1):77–84. doi:10.1007/s10549-017-4305-6
37. Althof SE, Parish SJ. Clinical interviewing techniques and sexuality questionnaires for male and female cancer patients. *J Sex Med.* 2013;10(S1):35–42. doi:10.1111/jsm.12035
38. Hoole J, Kanatas AN, Mitchell DA. Psychosexual therapy and education in patients treated for cancer of the head and neck. *Br J Oral Maxillofac Surg.* 2015;53(7):601–606. doi:10.1016/j.bjoms.2015.04.022