

Title : Sexual health at 5 years after diagnosis of head and neck cancer

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Abstract

Purpose Sexual health (SH) is an emerging concern in the assessment of quality of life in patients surviving head and neck cancer (HNC). Using data from the French National Prospective VICAN Survey, this study aimed to assess SH deterioration five years after HNC diagnosis and related factors.

Methods Using univariate and multivariate analyses were performed in the 241 HNC survivors. We studied the factors associated between the sexuality and intimate life of these patients with demographic and medical data from the national epidemiological survey VICAN 5.

Results Sexuality and body image were altered in 78,8% for men and 79,2% for women. This alteration in sexual quality of life affects both men and women. Dissatisfaction with the frequency of sexual intercourse was associated with being treated with radiotherapy ($p=0.024$), as well as decrease of sexual desire in patients treated with chemotherapy ($p=0.044$). Fatigue ($p=0.002$), impaired physical health ($p=0.049$) and high disease stage ($p=0.001$) remained significantly associated, after multivariate analysis, with decreased sexual desire. Among these 3 factors negatively influencing sexual quality of life, two are treatable with appropriate management.

Conclusion Five years after the diagnosis of HNC, a decrease in sexuality and body image are frequent and significantly impact the quality of life of survivors. These observations imply an adaptation of the management of the professionals involved.

Keywords: Oncosexuality – Head and neck cancer - Quality of life - VICAN study - sexual health

Introduction

Recently, sexual quality of life has emerged as an integral component of overall quality of life [1], including in cancer patients which may attach high importance to their sexual health [2]. Moreover, the maintenance of good sexual health has been shown to have a positive impact on the progression of cancer disease and treatment response [3, 4]. However, sexual dysfunction is one of the major and frequent consequences of cancer and its treatment [5]. The role of onco-sexuality in the management of cancer has already been studied extensively for urogynecological cancers [6]. Recently, a working group of the Institut National du Cancer (INCa) has elaborated recommendations on the preservation of sexual health aiming to provide cancer professionals, with the basic knowledge to prevent and treat complications related to sexual health [7]. As concerning Head and Neck Cancer (HNC), sexual issues may be of major concern, especially because this area represents the main element of the relational sphere.

All treatment modalities have many effects over patients' quality of life in HNC patients, such as the compromising of speaking and swallow, decrease in taste and smell, sputum, xerostomia and social isolation [8, 9]. These sequelae interfered with sexual life, intimacy and body image [10, 11]. Thus, these patients must cope not only with the diagnosis, treatment and treatment sequelae of cancer, but also with consequences of a social nature as well [12]. Especially, the visible facial disfigurement and related functional disorders associated with head and neck cancer treatment predispose these patients to unique physiologic and psychosocial needs [12].

There are very few specific studies studying sexual health in the field of HNC. As a preliminary study, Psoter et al. examined quality of life in HNC patients at various periods of the disease and treatment and observed that overall quality of life was negatively correlated with sexual issues [13]. As concerning factors associated with sexual issues, although not consistent through the studies, younger HNC survivors seem more likely to have problems with sexuality [10, 14]. Singer and colleagues' study showed that survivors with advanced tumor stage reported more often of sexual difficulties [15]. No studies indicated differences in sexuality based on tumor location or treatment, while results are not consistent through the studies [14, 15]. Finally, only two publications examined sexuality in patients with HNC using a qualitative approach and none of the existing studies had a longitudinal design [16, 17].

In the view of the paucity of existing literature, the aim of our study was to analyze the sexual health status at five years after the diagnosis of HNC and to identify factors associated with sexuality or body image disorders.

Materials and Methods

Description of the VICAN study and population

This study was conducted between 2010 and 2015 and is part of the national. The objective of the VICAN survey was to document the living conditions of cancer survivors at two time points: 2 and 5 years after diagnosis. In 2012, the first VICAN survey focused on analysis of data 2 years after diagnosis. This article is based on the second survey conducted in 2015, thus at 5 years after cancer diagnosis, aiming to analyze data on survivors at a longer time point.

Patients were aged 18 to 82 years at diagnosis, between January and June 2010. Participants were selected from the three main French health insurance schemes, which cover over 90% of the French population. Survivors living outside of France, deceased, with severe psychological disorders, or with another cancer, were excluded. Then, a random selection was made using sampling frames to obtain enough respondents, assuming a 33% response rate to the questionnaires. To be included in the study, participants had to be able to speak French, have sufficient cognitive abilities, and reside in private housing. A consent form was sent by the French health insurance to the selected survivors. An inclusion questionnaire was attached to the document. To be included, patients had to return the signed consent form and the inclusion questionnaire. Secondly, a medical survey was conducted with the physician who initiated the cancer treatment in order to fill in the medical data. The detailed methodology was previously published by Bouhnik et al. [18].

Finally, from this population of cancer survivors, we selected survivors with confirmed cancer of the oral cavity, oropharynx, hypopharynx, larynx, nasopharynx, nasal or sinus cavities, middle ear, and salivary glands.

The population of the present study was previously described by Dugue et al. [19], in the context of pain.

Measures studied

The VICAN questionnaires assessed socio-eco-demographic background, diagnosis, treatment, side effects, couple relationships and sexuality, relationships with health professionals and lifestyle outcomes, through closed questions. Clinical data, such as location, histology, stage, and types of treatment were collected in medical records.

We have focused our attention on evaluating :

Anxiety and depression were measured using the validated HAD scale [20]. Fatigue was assessed using the European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ C30

[21]) fatigue subscale. A score equal equal or greater than 40 was considered as clinically relevant to identify severe fatigue [22].

Physical and mental health, were assessed using the validated Short Form-12 (SF12), consisting of 12 items [23]. Impaired physical health was found if the score was below 50 and below 42 for the mental health score (according to the Youden index).

Sexual health, was evaluated using the Relation and Sexuality Scale (RSS) [24]. Five items assessing evolution of satisfaction with relational aspects and sexual activity were used in the VICAN survey interviews at 5 years after diagnosis, as compared with diagnosis. Each item of the scale was validated individually.

- Sexual desire (increase/no difference/decrease/ disappearance/inadequate question).
- Achievement of orgasm (increase/no difference/decrease/ disappearance/inadequate question).
- Perceived change in frequency of sexual intercourse since diagnosis (increase/no difference/decrease/disappearance/inadequate question).
- Satisfaction with frequency of sexual intercourse (enormously/very/enough/little/not at all)
- Satisfaction with frequency of hugs and kisses (enormously/very/ enough/little/not at all).

Answers were categorized into “the cancer had a negative influence” if the participants answered “decreased or all gone” or “little or no satisfaction,” or into “the cancer had no negative influence” if they responded “increased or no difference” or “enormously, very or enough.”

Body image was assessed through 2 items used in the Six-Item State Self-Esteem Scale (SSES-6) [25]. Each item of SEES was validated individually:

- Do you feel self-conscious about your appearance (Strongly agree / Somewhat agree / Somewhat disagree / Strongly disagree)
- Do you feel less sexually attractive because of your illness or treatment (Strongly agree / Somewhat agree / Somewhat disagree / Strongly disagree)

Endpoints

The primary objective of this study is to assess sexual desire, as it the first step of sexuality (1-desire / 2-plateau phase / 3-orgasm / 4-resolution), and it applies to all individuals, regardless of their marital status (in couple or not), and then to identify factors associated with decrease in sexual desire. Secondary objectives include

description of patients not responding to sexual desire items, as well as sexual quality-of-life according to treatment.

Ethical aspect

Three French national ethics commissions approved the VICAN methodology: CCTIRS (Comité Consultatif sur le Traitement de l'Information en Matière de Recherche dans le Domaine de la Santé, study n° 11-143), ISP (Institut de Santé Publique, study n° C11-63), and CNIL (Commission Nationale de l'Informatique et des Libertés, study n° 911290).

Statistical analysis

The associations between sexual health, intimate life, body image, and the patient's characteristics (age, sex, marital status, level of education), their disease (location, treatments received) and the sequelae (pain, fatigue, physical and mental health, xerostomia) were measured using the bilateral Chi2 test for categorical variables, or Student's t test for quantitative variables. A logistic regression model was constructed to evaluate the factors predicting a decrease or disappearance of sexual desire at 5 years after diagnosis. Factors significantly associated in univariate analysis at a 5% alpha risk were retained in a multivariate model. A step-wise model selection was then used to identify independent predictors of decreased or lost sexual desire. Statistical analyses were conducted with R software, version 4.1.1, and a two-sided alpha risk of 5% was retained as significant.

Results

Study population characteristics

Among 296 survivor patients with HNC in VICAN5 study, 55 patients (18.6%) did not respond to the question about sexual desire, accounting for 241 HNC survivors in the analysis dataset of sexual quality of life (**Figure 1**).

Of 241 patients, the majority of patients were over 55 years of age (156 patients, 64.7%) at the time of diagnosis and 193 (80.1%) were men. Indeed, treatment modalities are not exclusive. The most common treatment sequence was surgery followed by radiochemotherapy in 57 patients (23.7%) who met the primary endpoint. Then, surgery only in 53 patients (22%) who met the primary endpoint. Surgery was the most represented treatment in all treatment sequences (56.8%). The most represented location were the oropharynx (37.8%), followed by oral cavity (25.7%) and hypopharynx/larynx (24.5%). All the patients included in the study survived at 5 years after diagnosis. The main patient, tumor, and treatment characteristics are presented in **Table 1**, with characteristics of non-responding patients, for comparison.

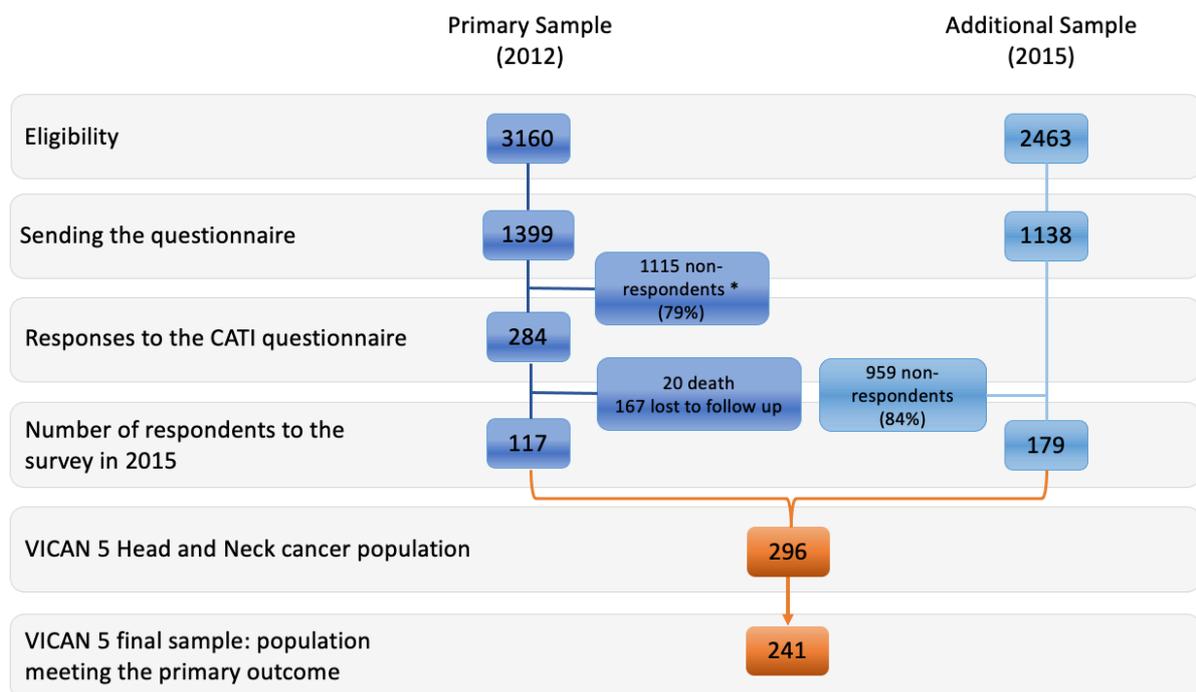


Figure 1: Flow chart. *No significant difference was found between the eligible patients who responded to the survey in comparison to those who did not, for the gender, age, tumor stage, and socioeconomic hardship index

[18]. CATI: Computer-assisted telephone interview; VICAN: Vie après le CANcer, French version for "Life after cancer" survey.

	Respondent at primary endpoint		Not respondent at primary endpoint		p-value
	N=241	%	N=55	%	
AGE at time of the diagnosis					<0.001*
18-54 years	85	35.3	5	9.1	
≥ 55 years	156	64.7	50	90.9	
GENDER					0.031*
Male	193	80.1	36	65.5	
Female	48	19.9	19	34.5	
MARITAL STATUS					0.002*
Single	32	13.3	2	3.6	
Married	148	61.4	36	65.5	
Widows / Widower	16	6.6	10	18.2	
Separated/Divorced	44	18.3	5	9.1	
No answer	1	0.4	2	3.6	
CHILDREN					0.350
Yes	209	86.7	48	87.3	
No	29	12	5	9.1	
No answer	3	1.2	2	3.6	
LEVEL OF EDUCATION					<0.001*
Less than high school degree	132	54.8	46	83.6	
High school degree or more	105	43.6	6	10.9	
No answer	4	1.7	3	5.5	
PRIMARY TUMOR SITE					0.070
Oral cavity	62	25.7	17	30.9	
Oropharynx	91	37.8	11	20	
Hypopharynx/larynx	59	24.5	21	38.2	
Salivary glands Rhinopharynx /	8	3.3	2	3.6	
Nasopharynx/nasal/cavity/sinus/middle ear	21	8.7	4	7.3	
STAGE AJCC AT DIAGNOSIS					1.000
I-II	76	38.2	17	37.8	
III-IV	123	61.8	28	62.2	
TRETEMENT					
Radiotherapy	131	54.4	27	49.1	0.580
Chemotherapy	91	37.8	23	41.8	0.690
Surgery	137	56.8	29	52.7	0.120

Table 1: Sociodemographic and medical characteristics of the Head and Neck cancer survivors. AJCC: American Joint Committee on Cancer

Difference between respondents and non-respondents

We noted that patients aged ≥ 55 years and female had a higher non-response rate ($p < 0.001$ and $p = 0.031$, respectively). Further, distribution of marital status as well as education level were significantly different between respondents and non-respondents (respectively $p = 0.002$ and $p < 0.001$). However, location, cancer stage and type of treatment did not differ between respondents and non-respondents survivors..

Alteration of sexual quality of life and body image (Table 2)

Desire was affected in 49.4% of patients. The impact on the frequency of sexual intercourse remained the most affected item, with 59.7% of survivors complaining of a decrease in intercourse. Body image items were the most frequently reported items, with a maximum of 14 missing responses, compared to sexual quality of life items accounting up to 91 missing responses. Sexuality and body image were altered in 78.8%. Among all the 241 patients responding to the primary endpoint, there was no significant difference in alteration of sexual quality of life or body image between men and women. No significant difference of rate of missing item between male and female was observed (data not shown).

	Total N=241	Female N=48	Male N=193	p-value
Sexual quality of life				
- Desire disorder	119 (49.4%)	28 (58.3%)	91 (47.2%)	0.220
- Insatisfaction with frequency of hugging and kissing	44 (29.3%)	12 (41.4%)	32 (26.4%)	0.170
Missing	91	19	72	
- Decrease frequency of sexual intercourse	120 (59.7%)	24 (61.5%)	96 (59.3%)	0.940
Missing	40	9	31	
- Insatisfaction with frequency of intercourse	77 (42.1%)	14 (43.8%)	63 (41.7%)	0.990
Missing	58	16	42	
- Decrease in possibility to reach orgasm	94 (49.0%)	19 (54.3%)	75 (47.2%)	0.560
Missing	47	13	34	
Body image				
- Embarrassment regarding appearance	95 (40.3%)	21 (44.7%)	74 (39.2%)	0.600
Missing	5	1	4	
- Feeling less attractive	80 (35.2%)	18 (40%)	62 (34.1%)	0.570

Missing	14	3	11	
Alteration of sexual quality of life or body image		n=48	n=193	
- No	51 (21.2%)	10 (20.8%)	41 (21.2%)	1.000
- Yes	190 (78.8%)	38 (79.2%)	152 (78.8%)	

Table 2: Decrease sexual quality of life and body image by gender since 5 years after diagnosis, univariate analyses, VICAN (Vie après le CANcer) survey

Factors associated with decreased sexual desire (Table 3)

In univariate analyses, several factors were associated with a decrease/disappearance in sexual desire: fatigue, depression, anxiety, altered mental and physical health, pain, xerostomia, oncological stage, as well as decreased gestures of affection and feelings of being less attractive.

In multivariable analysis, there was a significant impact of fatigue in decrease of sexual desire (OR = 1.20, 95% CI = [1.07-1.36], p = 0.002). Similarly, AJCC (American Joint Committee on Cancer) stage has a significant factor of decrease in sexual desire (OR = 2.85, 95% CI = [1.51-5.46], p = 0.001). The last point concerns the physical score, with higher score associated with lower decrease in sexual desire (OR = 0.50, 95% CI = [0.25-0.98], p = 0.049).

N=241	Univariable			Multivariable			Multivariable backward selection		
	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
Age >55	1.15	[0.68-1.96]	0.590						
Female	1.57	[0.83-3.01]	0.170						
Comorbidities score	1.45	[0.83-2.58]	0.190						
Fatigue (+10pt increase)	1.26	[1.15-1.39]	<0.001*	1.15	[0.99-1.34]	0.060	1.2	[1.07-1.36]	0.002*
Depression	3.27	[1.77-6.23]	<0.001*	1.54	[0.63-3.81]	0.340			
Anxiety	2.36	[1.41-3.98]	0.001*	1.32	[0.65-2.65]	0.440			
10% Weight loss	1.51	[0.86-2.69]	0.160						
Physical health >=50	0.27	[0.16-0.47]	<0.001*	0.51	[0.24-1.07]	0.080	0.5	[0.25-0.98]	0.049*
Mental health >=42	0.34	[0.20-0.59]	<0.001*	0.77	[0.34-1.78]	0.540			
Pain	2.57	[1.43-4.76]	0.002*	1.05	[0.47-2.33]	0.910			
Xerostomia	1.96	[1.15-3.38]	0.014*	0.97	[0.46-2.01]	0.930			
Surgery	0.8	[0.48-1.33]	0.380						
Radiotherapy	1.25	[0.75-2.08]	0.390						
Chemotherapy	1.78	[1.05-3.02]	0.033*	0.93	[0.45-1.88]	0.830			
Tumor site			0.690						
<i>Oropharynx</i>	1								
<i>Hypopharynx_Larynx</i>	0.81	[0.42-1.55]	0.520						
<i>Oral cavity</i>	1.33	[0.69-2.55]	0.400						
<i>Salivary glands</i>	1.02	[0.23-4.56]	0.980						
<i>Nasopharynx/nasal/cavity/sinus/middle ear</i>	0.77	[0.29-1.99]	0.590						
Stage AJCC III/IV**	3.08	[1.71-5.68]	<0.001*	2.83	[1.39-5.86]	0.004*	2.85	[1.51-5.46]	0.001*
Deterioration of couple relationships***	2.64	[0.94-8.61]	0.080						
Less affectionate gestures***	5.18	[2.39-12.10]	<0.001*						
Feeling less attractive	1.99	[1.15-3.50]	0.015*	0.69	[0.30-1.56]	0.390			
Dissatisfaction with the scar	1.4	[0.72-2.78]	0.330						

Table 3 : Factors associated with the decreased or all gone sexual desire among Head and Neck cancer survivors, 5 years after diagnosis—univariate analyses—VICAN (Vie après le CANcer) survey (n = 241)

* Statistically significant results

** 42 missing data

*** Only on patients living in a couple (n=171)

Alteration of sexual quality of life according to treatment (Table 4).

Surgery was not associated with decreasing sexual quality of life or body image. We found a statistically significant decrease in sexual intercourse for patients treated with radiotherapy (p=0.024) as compared to those who were not

treated. Further, chemotherapy treatment had a negative impact on sexual desire ($p=0.044$) as well as on body image criteria ($p=0.052$ and $p=0.037$).

Treatment	With	Without	<i>p</i> -value
Surgery	137	103	
Sexual quality of life			
- Decreased desir	64 (46.7%)	54 (52.4%)	0.460
- Insatisfaction with frequency of hugging and kissing	25 (26.6%)	18 (32.7%)	0.540
- Decrease frequency of sexual intercourse	65 (55.6%)	54 (65.1%)	0.230
- Insatisfaction with frequency of intercourse	45 (42.5%)	31 (40.8%)	0.940
- Decrease in possibility to reach orgasme	51 (45.1%)	42 (52.5%)	0.390
Body image			
- Embarrassment regarding appearance	55 (40.7%)	39 (39%)	0.890
- Feeling less attractive	42 (32.6%)	37 (38.1%)	0.460
Radiotherapy	N=131	N=110	
Sexual quality of life			
- Decreased desir	68 (51.9%)	51 (46.4%)	0.470
- Insatisfaction with frequency of hugging and kissing	28 (35%)	16 (22.9%)	0.150
- Decrease frequency of sexual intercourse	67 (62.6%)	53 (56.4%)	0.450
- Insatisfaction with frequency of intercourse	48 (50.5%)	29 (33%)	0.024*
- Decrease in possibility to reach orgasme	51 (47.7%)	43 (49.4%)	0.920
Body image			
- Embarrassment regarding appearance	59 (46.1%)	36 (33.3%)	0.063
- Feeling less attractive	48 (40%)	32 (29.9%)	0.150
Chemotherapy			
Sexual quality of life			
- Decreased desir	53 (58.2%)	66 (44%)	0.044*
- Insatisfaction with frequency of hugging and kissing	15 (27.3%)	29 (30.5%)	0.810
- Decrease frequency of sexual intercourse	49 (65.3%)	71 (56.3%)	0.270
- Insatisfaction with frequency of intercourse	34 (48.6%)	43 (38.1%)	0.210
- Decrease in possibility to reach orgasme	38 (50.7%)	56 (47.1%)	0.730
Body image			
- Embarrassment regarding appearance	43 (48.9%)	52 (35.1%)	0.052
- Feeling less attractive	37 (44.6%)	43 (29.9%)	0.037*

Table 4 : Decrease sexual quality of life and body image depending on treatment since 5 years after diagnosis, univariate analyses, VICAN (Vie après le CANcer) survey

* Statistically significant results

Discussion

Using a large sample of 296 HNC patients from the national wide and representative VICAN study of cancer survivors, we found that 81.4% responded to questionnaire about sexual desire, of which the half expressed altered sexual desire five years after diagnosis. Fatigue, physical health and disease stage were shown to be independently associated with sexual desire alteration. Furthermore, sexuality and body image were altered in almost 80% HNC survivors. Although the responding rate was higher for male, no difference of sexual quality-of-life and body image was observed between genders. As concerning treatments, radiotherapy and chemotherapy were shown to slightly impact sexual quality-of-life, but not surgery.

Part 1: impact of HNC on desire

Our results confirm previous work on sexual dysfunctions, which are not limited to patients suffering from urogenital cancers [26] with sexual symbolism, but also to all cancers. In the VICAN 5 study, in all locations combined, we observed that cancers of the VADS are those causing the most discomfort in relation to appearance, just after sex-dependent cancers [27].

We found that nearly half of the respondents (49,4%) perceived their sexual life as less satisfying than before cancer all locations combined. This dissatisfaction of half of the patients is found at different scales, with Singer et al. on 88 laryngectomees [15], 53% of patients reported less interest in sex and 48% reported decreased libido. More generally, Heyne et al. [28], studied the impact in sexual satisfaction among long-term cancer survivors 5 and 10 years after diagnosis (all cancers combined), patients were less satisfied (48.9%) with sexuality at the time of the survey. There still persists a large variability of results, even within the same surgery, for example the impairment of desire in laryngectomized patients was impaired from 5% for Hirani et al. [29] to 90% for Batioğlu-Karaaltın et al. [30]. Unfortunately, time does not seem to allow an improvement [28].

In addition to the aspect of sexual desire, almost 80% of the respondents presented an alteration in their sexual quality of life or body image. This double component is not found in the literature for ENT cancers, but similar rates of alteration (77%) are found in gynecological cancers [6].

Part 2 : Respondent/nonrespondent population

In this study, we observed a non-responder rate of 18.6% (55/296 patients) when assessing sexual desire, which is still slightly better than in other studies on the subject with abstention rates of 23-29% [10, 31]. Many clinical factors were associated with non-responding issue. Indeed, patients with a level of education less than high school

degree, were more likely not to answer the questionnaire and therefore to exclude themselves from sexuality problems. Indeed, many studies have shown that education positively influences quality of life by improving the patient's ability to question and communicate with health professionals [32, 33]. This results in social isolation and avoidance of intimate relationships, particularly because of embarrassment about their appearance.

A significantly lower response rate was also observed in patients older than 55 years. This aspect of abstention in older subjects has not been found in the literature, but it would seem that age has a negative influence on sexual quality of life [34]. The fact of having an alteration in the criteria studied remains a brake on participation in surveys by questionnaires.

We also found that refusal to answer the sexuality questionnaires was more common in the female population. This was the case for many other sites in the VICAN 5 study, and according to our results in HNC location was no exception. This is one of the major limitations highlighted by sexual quality of life studies [10, 31].

Paradoxically to our beliefs [34], we noticed that single and divorced people had a higher response rate. However, this is a population often overlooked in this type of study, which only adds to the sense of shame, frustration and isolation for survivors. It is essential to also assess non-coupled individuals about their sexuality and body image.

Part 3: Factors associated with altered desire

Our present analysis showed that the deterioration of sexual quality of life affected both men and women, with no significant difference. These results are surprising because in the literature we often find a lower sexual quality of life in women [35]. Undoubtedly, damage to body image linked to the visible after-effects remains more difficult to support for women. This tendency is also found in many studies on quality of life in cancer therapy [36].

Similarly, age is not a significant criterion for alteration of sexual quality of life or body image, but it appears to be a factor in the severity of self-perception depreciation. Several authors highlighted the accumulation of age- and cancer-related sexual dysfunctions in elderly patients, while showing a decrease in the negative impact of the gaze of others on appearance [10, 12]. One explanation could be the high rate of non-response in our study in patients over 55 years of age, responsible for a selection bias.

High stage cancers are strongly correlated with an alteration of sexual desire and thus of the sexual quality of life, independently of the treatments received. Indeed, the literature remains univocal on this item with regard to overall quality of life [37, 38], but this is less certain and can still be studied with regard to sexual quality of life [10]. All the studies reporting a lower quality of life for high stage carcinoma attribute this mainly to the more debilitating treatment and management [39], which may be questioned in our study, since it is an independent factor.

Five years after the diagnosis of HNC, a very large proportion of patients reported suffering from sequelae related to the disease and/or treatments. Fatigue, depression, anxiety, altered mental and physical health, pain and xerostomia are directly involved in the decrease of sexual desire. After elimination of confounding factors, fatigue and physical health are still associated with decreased sexual desire. For these complications, specific management is possible and can significantly improve the overall quality of life, including psychological and medication management [40], as well as exercise rehabilitation [41]. Moreover, it has been recently demonstrated that patients suffering from HNC have a 4 times higher risk of developing sleep apnea syndrome [42], treatable by positive pressure nocturnal ventilation, but we still have to think about this in the follow-up of our patients.

In spite of this, in the VICAN 5 study, all locations taken together, only 28% of the patients declared that they had received specific management of their sequelae. This translates into two thirds of patients who did not feel adequately managed in terms of post-treatment sequelae [27].

Part 4: impact of chemo and radiotherapy on sexual life

Radiotherapy and chemotherapy seemed to be the treatments affecting sexuality, with a significant negative impact respectively on the frequency of sexual intercourse and the decrease in sexual desire. Surprisingly, we found no correlation between altered sexuality and surgery, even though most studies on the subject highlight a body image problem associated with head and neck surgery [12, 34, 43]. This would lead to an alteration of body image that could lead to a feeling of shame and social isolation. Our finding was also confirmed by Lahtinen et al. who demonstrated that the quality of life of patients who underwent major surgery with complex flap reconstruction was equivalent to that of the general population [44].

With regard to chemotherapy treatment, there was a significant impact on the decrease in sexual desire, as well as a deterioration of body image. Chemotherapy appears to be the oncological treatment most associated with a high level of emotional and physical distress in the literature [45]. This is understandable given the place of chemotherapy in ENT treatment protocols, proposed for metastatic or locally advanced cancers not accessible to surgery, with consequently a more altered general state from the start [46].

Part 5 : strengths and weaknesses

One of the main strengths of this work is the large of data analyzed and the number of patients included on a subject as taboo as sexuality. The demographic and medical data were detailed and reliable, coming from national medico-administrative sources. Unlike many studies on the subject, our analyses examined a wide range of factors,

from purely demographic factors (age, sex) to medical factors (tumor topography, type of treatment) and psychosocial factors (marital life, level of education). In order to reduce bias in all the elements studied by VICAN, several questions targeting the same item were asked, which limited the risk of non-comprehension by the patient.

However, some limitations deserve to be raised. The representativeness of this study remains debatable. In my opinion, the inclusion design of the study implies a representativeness of the HNC population in metropolitan France at five years of diagnosis. But, the respondent/non-respondent populations imply a selection bias, but this is already recognized and immutable in all studies on the subject.

Moreover, this vast survey was subject to participation, resulting in a significant number of missing data with absences of answers but also refusals to answer, particularly on the questions concerning intimate life. Most of the items are declarative and therefore subject to interpretation of the questions by the patients. In the same way, the relevance of the way some questions are phrased can be discussed. In particular, the questions concerning the frequency of sexual intercourse. In our study, this was reported as "decreased" in a majority of cases. However, it should be emphasized that the sexual quality of life is not so much related to the frequency of intercourse, but rather to the overall satisfaction felt by the patients. For example, in a study of laryngectomized patients, it was observed that the frequency of sexual intercourse had decreased by 60%, while 58% of the patients declared themselves "more" or "equally" satisfied with their sexuality [47]. Similarly, there is the question of the social acceptance of having a troubled sex life, especially in the male population, and the fact of being able to assume it on a questionnaire. This limitation could be exacerbated in the VADS population, which is mainly male, with an alcohol-smoking background and an often unfavorable socioeconomic environment [38].

Nevertheless, the incorporation of 5 items from the Relation and Sexuality Scale (RSS), allows a validated scientific recognition. We have addressed the main items of sexual quality of life: desire, frequency and satisfaction of sexual intercourse and the ability to have an orgasm, to which we have added 2 items concerning body image. By assessing quality of life five years after diagnosis, VICAN 5 study allows to measure the evolution of survivors' quality of life in the long term. However, the physiological aging is often associated with a decrease in sexual activity and may interfere with observed results [48]. In fact, from the age of 50, men can present a decreased libido; the desire, the sexual thoughts can be reduced [48]. Similarly, at this age, spontaneous erections decrease and their quality diminishes, as do orgasms [49]. At the same time, biological changes were observed with a decrease of 0.4% per year in total testosterone, constituting a limiting factor for sexuality over time [50].

In women, testosterone levels decreased by one third progressively during the 20 years following adolescence, but remained stable during the menopause and after [51]. On the other hand, after the menopause there is a decrease in vaginal lubrication, associated with urogenital atrophy due to the fall in estrogen levels, making the vaginal mucosa more sensitive to trauma related to sexual activity [52]. All of these natural physical and biological alterations in women and men contributed to an alteration in sexual desire [53].

Our recommendations :

It is now well accepted that the onset of cancer and the treatments implemented can have a major deleterious impact on sexuality and body image. These consequences occur even if the cancer does not directly affect the urogenital tract, and our work corroborates this observation. However, to date, there is still no real French national recommendation for prevention of sexual health after HNC. We wish to promote specific short and long term management of post-treatment sequelae, which is essential to prevent sexual disorders. We agree with Rothen et al [54], that better communication and training of health professionals in onco-sexuality seems to be one of the major avenues to improve our management in this area as well as to integrate our patients into the exercise rehabilitation program. With regard to fatigue, oncology practitioners should be aware of the increased risk of sleep apnea syndrome in patients with HNC, and when complaints of fatigue and sleeping problems persist, referral to a sleep clinic is suggested.

Conclusion

Our work has shown that the population of patients with HNC reported a significant deterioration in their sexual relationship and body image at 5 years. We have highlighted several associated factors, some of which can be improved (fatigue/physical health) by an evolution of our professional practices. The integration of sexual health in our management from the time of diagnosis, the involvement of the spouse, the training of health professionals on this subject, as well as the early management of the after-effects constitute avenues for improvement to optimize the experience of these patients.

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Availability of data and material The data that support the findings of this study are available from UMR 912 SESSTIM(INSERM). Restrictions apply to the availability of these data, which were used under license for this study. Data are available from the authors with the permission of UMR 912 SESSTIM(INSERM).

Code availability Not applicable.

Authors' contributions

Concept and design: Humbert, Rhamati, Babin

Acquisition, analysis or interpretation of data: Humbert, Rhamati, Bouhnik and Babin.

Drafting of the manuscript: Humbert, Rhamati, Babin and Huygue

Critical revision of the manuscript for important intellectual content: Dugue, Bon-Mardion, Licaj and Babin.

Statistical analysis: Lequesne, Licaj.

Administrative, technical or material support: Humbert, Lequesne, Bouhnik, Licaj.

Supervision: Babin, Bon-Mardion and Huygue.

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Declarations

Ethics approval The methodology was approved by three national ethics commissions: the CCTIRS (Advisory Committee for Data Processing in Health Research, study registered under n°11-143), the ISP (Institute of Public Health, study registered under n°C11-63) and the CNIL (French Commission on Individual Data Protection and Public Liberties, study registered under n°911290). Confidentiality is assured for all participants regarding any personal responses and information provided, as all data collected were anonymized. The study was in accordance with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Consent to participate Each selected survivor received a letter from the National Health Insurance Fund inviting him/her to participate in the survey. Participants had to sign and send back an informed consent form.

Consent for publication Not applicable. Confidentiality is assured for all participants regarding any personal responses and information provided, as all data collected were anonymized.

Conflict of interest The authors declare that they have no conflict of interest.

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