



Quality of Life of the Patient with Head and Neck Cancer Submitted to Radiotherapy and the Overload of Their Caregivers

Daniela Delalibera¹ Alessandra Cristine Ribeiro Carvalho¹ Bruna Luiza Thesolim¹
 Laura Ferreira de Rezende¹

¹ Centro Universitário das Faculdades Associadas de Ensino (UNIFAE), São João da Boa Vista, SP, Brazil

Address for correspondence Daniela Delalibera, Master, Rua Floriano Peixoto, 938, SP, Brasil (e-mail: danidelalibera@gmail.com).

Int Arch Otorhinolaryngol 2021;25(4):e536–e544.

Abstract

Introduction Esthetic and functional changes are frequent in patients with head and neck cancer, and they can be caused by both tumor and treatment. Physical and functional impairment often requires the need of a caregiver, who may feel overwhelmed with the tasks of care.

Objective This study aims to evaluate the quality of life of patients with head and neck cancer submitted to radiotherapy and the overload of their caregivers.

Method This is a quantitative cross-sectional study with 42 patients with head and neck cancer and 17 caregivers evaluated during the radiotherapy treatment. Patients responded to the following questionnaires: Functional Assessment of Cancer Therapy for Head and Neck Cancer (FACT-H&N) and Shame and Stigma Scale (SSS), while the caregivers responded to the Zarit Burden Interview Scale (ZBI) and Palliative Performance Scale (PPS).

Results Head and neck cancer patients showed a decline in the quality of life in all FACT-H&N domains, with the domain of additional concerns having the worst outcome. Among the feelings reported by patients, the most important was penitence. Less than half of the patients needed caregivers. It was observed that the greater the degree of commitment of the patient, the greater the degree of overload of the caregiver.

Conclusion Therefore, the quality of life of the patient with head and neck cancer is an important aspect to be considered during the therapeutic choice and in the follow-up of the patient, since it has influenced both the patient and his caregiver.

Keywords

- ▶ head and neck neoplasms
- ▶ quality of life
- ▶ caregivers
- ▶ radiotherapy

Introduction

Head and neck cancer (HNC) is the sixth cause of malignant neoplasms in the world and represents a set of tumors that affect the anatomical structures of the oral and nasal cavity, paranasal sinuses, pharynx, larynx, salivary glands and thyroid gland. The most prevalent histological type is squamous cell carcinoma,

which accounts for ~90% of all cases. In Brazil, it is estimated that around 450,000 new cancer cases will occur in 2020 (excluding cases of non-melanoma skin cancer), of which 15,190 will be of the oral cavity, and 7,650 will be laryngeal neoplasms.^{1–7}

The treatment of HNC consists of surgery, radiotherapy and chemotherapy or a combination of these approaches. Often, depending on both tumor location/extent and

received
November 25, 2019
accepted
August 30, 2020
published online
February 19, 2021

DOI <https://doi.org/10.1055/s-0040-1718963>.
ISSN 1809-9777.

© 2021. Fundação Otorrinolaringologia. All rights reserved.
 This is an open access article published by Thieme under the terms of the Creative Commons Attribution-NonDerivative-NonCommercial-License, permitting copying and reproduction so long as the original work is given appropriate credit. Contents may not be used for commercial purposes, or adapted, remixed, transformed or built upon. (<https://creativecommons.org/licenses/by-nc-nd/4.0/>)
 Thieme Revinter Publicações Ltda., Rua do Matoso 170, Rio de Janeiro, RJ, CEP 20270-135, Brazil

treatments employed, the patient may have local deformities, as well as effects on basic functions such as speaking, breathing, swallowing and eating. These changes can leave patients distressed, with relational difficulties and social isolation, so, all changes resulting from the tumor and treatment can directly impact their quality of life.^{1,8–12}

The assessment of the quality of life of patients with head and neck cancer helps in optimizing the therapeutic choice, balancing the patient's needs and gains in the recovery, and, therefore, not based solely on tumor staging and clinical aspects.^{11,13,14}

Due to the physical and emotional impairment attributed to cancer, many patients need a caregiver, who is usually a family member. In patients with HNC, the caregiver is usually family-based and assumes various care responsibilities. These activities can have significant consequences and may overwhelm the caregiver. Factors that interfere with the caregiver burden are the time devoted to care, the available financial resources, the caregiver's psychological, physical and social conditions, and the burden derived from caregiving.^{15–18}

In this context, the present study aimed to evaluate the quality of life, shame, and stigma of patients with head and neck cancer undergoing radiotherapy as well as caregiver burden.

Method

Sample

Quantitative descriptive cross-sectional study conducted at Memorial Radiotherapy Clinic in the city of Poços de Caldas - MG, from April to December 2018. Recruitment occurred as the patient accompanied or not by his caregiver presented to perform the radiotherapy session, both invited to participate in the study. The sample included 42 participants with head and neck cancer and 17 caregivers. The work was approved by the ethics committee Centro Universitário das Faculdades Associadas de Ensino (UNIFAE) by CAAE: 83495118.7.0000.5382.

Inclusion criteria for the patient were: age over 18 years; confirmed diagnosis of head and neck cancer by histopathological examination; being on radiotherapy for cancer. The primary sites included were oral and nasal cavity, paranasal sinuses, pharynx, larynx, glands (parotid, submandibular and sublingual) and hidden primary tumor. For the caregivers, the following inclusion criteria were chosen: age over 18 years, stay with the patient for at least 4 hours a day and for at least 5 days a week, be aware of the patient's disease and be caregiver of the interviewed patient only. The exclusion criterion for both patient and caregiver was the impossibility of answering the questionnaires due to difficulty in understanding the questions.

The patient answered two questionnaires at the same time: Functional Assessment of Cancer Therapy for Patients with Head & Neck Cancer (FACT-H&N) -version 4.0 and Shame and Stigma Scale (SSS), translated and validated for Portuguese/Brazil.^{12,19,20}

The caregiver answered two questionnaires, the Zarit Burden Interview Scale (ZBI), to assess the caregiver burden,

and the Palliative Performance Scale (PPS), to assess the patient's dependence level, both translated and adapted to Portuguese/Brazil.^{21–23}

Data Analysis

For data analysis, we used the JASP version 0.9.0.1 statistical software (Eric-Jan Wagenmakers (room G 0.29) Department of Psychological Methods University of Amsterdam Nieuwe Achtergracht 129B Amsterdam, The Netherlands), with a confidence level of $p \leq 0.05$. In a preliminary way, descriptive measurements of all variables were surveyed, calculating the frequency and percentage of cases for each categorical measure and, for scalar measures, the mean and standard deviation values were obtained.

The Spearman correlation was performed to calculate the associations between the ordinal or scalar variables. Comparisons between two groups were made using the Mann-Whitney independent sample test. Nonparametric analyses were chosen because the values of the normality test (Shapiro-Wilk) suggested violations

Results

The study included 42 patients with head and neck cancer during treatment with radiotherapy. The characteristics and clinical data of the patients are described in ►Tables 1 and 2. There was a predominance of males, represented by 78.6% of the patients, the average age was 60.3 years (± 10.7), range 36–79. Of the respondents, 88.1% were not working at the time of the interview, and the average monthly income of the families was around 2.1 minimum wages (± 1.7).

The time elapsed between the 1st symptom and the beginning of treatment was on average 1 year and 4 months (± 1.5) with 95% CI (0.9–1.8). And the time interval between the 1st biopsy and treatment was 6 months on average, with SD (± 8.0) and 95% CI (3.6–8.4).

The diagnosis was made at a more advanced stage, and 71.4% of the patients were at stage III or IV at the time of treatment. It was also observed that the worse the staging, the higher the alcohol use and the daily dose ($p < 0.05$). Regarding quality of life, advanced staging showed worse FACT-H&N response to the additional concern domain ($p < 0.05$).

Of the patients interviewed, 18 (42.8%) had a caregiver, 24 did not need or did not have a caregiver, and only one caregiver refused to participate in the research. The caregivers were mostly female (64.7%); the average age was 45.6 years (± 14.9), with the minimum age being 25 and the maximum age 73; 58.8% were married; and 88.2% were Catholic, as shown in ►Table 3. Regarding family income, the average was 1.9 (± 1.0) minimum wages. Informal caregivers represented 100% of respondents, with 94.1% belonging to the family nucleus, and the average daily time devoted to care was 8.0 hours (± 2.5).

The FACT-H&N results are shown in ►Table 4. In the data analysis, when domains were evaluated, the additional concerns (H&N questions), which presents issues specific to both tumor and treatment symptoms, presented the worst response. Regarding the global scales, the worst was the Trial

Table 1 Description of patients and caregivers

	Categories	Patient <i>n</i> = 42		Caregiver <i>n</i> = 17	
		Value	% Total	Value	% Total
Gender	Female	9	21.4	11	64.7
	Male	33	78.6	6	35.3
Marital Status	Married	26	61.9	10	58.8
	Divorced	2	4.8	2	17.7
	Single	8	19.0	3	5.9
	Stable union	2	4.8	2	11.8
	Widower	4	9.5	0	0
Religion	Catholic	35	83.3	15	88.2
	Spiritism	1	2.4	0	–
	Evangelical	6	14.3	2	11.8
Educational level	Illiterate	4	9.5	0	–
	Incomplete elementary	22	52.4	9	52.9
	Complete elementary	6	14.3	2	11.8
	Incomplete high school	2	4.8	1	5.9
	Complete high school	4	9.5	4	23.5
	Incomplete university	1	2.4	1	5.9
	Complete university	3	7.1	0	–
Profession	Rural activity	10	24.4	1	5.9
	Cleaning assistant	2	4.7	0	–
	Hairdresser	2	4.7	0	–
	Merchant	2	4.7	1	5.9
	Seamstress	1	2.4	3	17.7
	From home	1	2.4	3	17.7
	Electrician	2	4.7	0	–
	Driver	4	9.7	1	5.9
	Baker	2	4.7	0	–
	Bricklayer	2	4.7	0	–
	General services	3	7.3	1	5.9
	Others	11	26.4	7	41.3

Table 2 Patient clinical data

Characteristic	Category	Primary subsite	Value	%	% Total	
Cancer type and location	Oral cavity		12		28.6	
		Lower gum	2	16.6	4.8	
		Tongue	4	33.3	9.5	
		Retromolar trigone	4	33.3	9.5	
		Not localizable	2	16.6	4.8	
		Pharynx		11		26.3
		Oropharynx		7	63.6	16.7
			Amygdala	5	71.4	11.9
			Tongue base	1	14.3	2.4
			Not localizable	1	14.3	2.4

Table 2 (Continued)

Characteristic	Category	Primary subsite	Value	%	% Total
	Rhinopharynx		2	18.2	4.8
	Hypopharynx		2	18.2	4.8
	Salivary glands		2		4.8
	Larynx		11		26.3
		Supraglottic	3	27.3	7.1
		Glottis	8	72.7	19.0
	Paranasal sinuses		1		2.4
	Hidden primary tumor		5		11.9
Histological type	Adenoid cystic carcinoma		1		2.4
	Undifferentiated carcinoma		3		7.1
	SCC		38		90.5
Staging	I		5		11.9
	II		5		11.9
	III		6		14.3
	IV		24		57.1
	Ignored		2		4.8
Treatment	Category		Value		% Total
Radiotherapy	Exclusive		8		19
	+ Chemotherapy		22		52.4
	+ Surgery		6		14.3
	+ Chemotherapy + surgery		6		14.3
No. of radiotherapy sessions	Mean (SD)		14.1 (10.9)		–
No. of chemotherapy sessions	Mean (SD)		4.0 (4.2)		–
Habit	Category		Value		% Total
Tobacco	Smoking ceased		29		69.0
	Active smoker		6		14.3
	Never smoked		7		16.7
Type of cigarette	Industrialized		24		68.6
	Handcrafted		7		20
	Both		4		11.4
Cigarettes a day	Mean (SD)		18.51 (11.34)		-
Consumption time (in years)	Mean (SD)		36.6 (14.78)		-
Alcoholic drink	Stop drinking		27		64.2
	Drink		1		2.4
	Never drank		14		33.4
Type of drink	Distilled drinks		22		78.6
	Beer		6		21.4
Consumption time (in years)	Mean (SD)		31.1 (13.7)		

Abbreviations: SD, standard deviation; SCC, squamous cell carcinoma.

Table 3 Descriptive related to care

Variable	Category	Value	% Total
Relationship	Wife	5	29.4
	Son/daughter	6	35.3
	Brother/sister	1	5.9
	Husband	2	11.8
	Unrelated	1	5.9
	Nephew/niece	1	5.9
Careful time (number of days of the week)	Mean	6.7	–
	SD	0.8	–
Account with help	Not	4	23.5
	Sometimes	6	35.3
	Ever	7	41.2

Abbreviation: SD, standard deviation.

Outcome Index (TOI) scale, which is the final total index of the physical and functional domains and additional concerns (H&N questions).

► **Table 5** presents the results obtained in the Shame and Stigma Scale (SSS). Evaluating the subscales, the one with the highest average was the feeling of regret (39.28%). The subscale that had the lowest impact among respondents was in relation to stigma. Although the issue of stigma and appearance is related to head and neck cancer, the scale had a global average of only 16.55% (± 16.14).

Patients with caregiver evaluated by the PPS had a mean dependence of 74.12% (± 15.43), and the highest degree of impairment was 50%; the closest to 100%, the lower the impairment. The degree of caregiver burden presented an average of 21.58 (± 12.94), and the higher the value, the higher the burden.

The correlations between each domain of the FACT-H&N questionnaire were positively related, as well as the correlations between each domain of the Shame and Stigma Scale (SSS), the analyzes with statistical significance are shown in ► **Table 6**.

Table 4 Descriptive analysis of the Functional Assessment of Cancer Therapy for Head and Neck Cancer questionnaire

	Scores	Mean	SD	Median	Min/ max	Proportional average to maximum possible score (%) (95% CI)
PWB	0–28	18.7	6.2	19	05–28	66.7 (59.9–73.4)
SWB	0–28	23.8	4.1	24.5	14–28	84.9 (80.4–89.4)
EWB	0–24	19.7	5.0	21.5	04–24	82.0 (75.8–88.3)
FWB	0–28	21.7	5.9	22.5	04–28	77.5 (71.1–83.8)
Additional concerns (H&N questions)	0–40	23.1	7.8	21.5	07–40	57.8 (51.9–63.7)
TOI	0–96	63.6	17.0	62.5	27–95	66.2 (60.9–71.5)
FACT- G	0–108	83.9	17.4	87.3	31–107	77.7 (72.8–82.5)
FACT-H&N	0–148	107.0	22.9	108.5	49–147	72.3 (67.6–77.0)

Abbreviations: CI, confidence interval; FACT-G, Functional Assessment of Cancer Therapy: General; FACT-H&N, Functional Assessment of Cancer Therapy for Head and Neck Cancer; EWB, emotional well-being; FWB, functional well-being; PWB, physical well-being; SD, standard deviation; SSS, Shame and Stigma Scale; SWB, social and family well-being; TOI, Trial Outcome Index.

Table 5 Descriptive analysis of the Shame and Stigma Scale (SSS)

	Mean %	SD	CI 95%
Shame with appearance	12.6	19.8	(6.7–18.6)
Sense of stigma	10.1	15.2	(5.5–14.7)
Regret	39.3	33.1	(29.3–49.3)
Speech/social concerns	17.1	24.9	(9.5–24.6)
Total score	16.5	16.1	(11.7–21.4)

Abbreviations: CI, confidence interval; SD, standard deviation.

The FACT-H&N instruments and the Shame and Stigma Scale showed a negative correlation between some of their domains. Relevant results are shown in ► **Table 7**.

The Zarit scale, which assessed caregiver burden, was negatively correlated with SPP, Spearman's rho of -0.562 and $p < 0.5$, the greater the decline in basic functions, the greater the caregiver burden. Moreover, the fact that the caregiver counted on someone's help revealed a negative correlation with Zarit scale with $p < 0.05$.

Quality of life was related to the need for a caregiver, since patients who needed a caregiver had a lower quality of life than patients who did not need care ($p < 0.05$), especially in the domains: physical well-being, social and family well-being, functional well-being, and also in relation to the global domains: TOI, Functional Assessment of Cancer Therapy: General (FACT-G), FACT-H&N, described in ► **Table 8**. When comparing the answers obtained in the FACT-H&N questionnaire, there was no statistically significant difference between male and female patients. There was also no significance between the answers obtained on the SSS comparing patients with and without caregivers and also between male and female patients.

Discussion

The patients in this study presented a sociodemographic characterization very similar to that reported in the

Table 6 Correlation between domains

Correlation Between FACT-H&N Domains (Spearman's Rho Positive)			
Subscale	FACT-H&N		p
PWB	SWB	**	0.007
	EWB; FWB; H&N questions; TOI; FACT-G; FACT-H&N	***	< 0.001
SWB	H&N questions	*	0.018
	FWB; TOI; FACT-G; FACT-H&N	***	< 0.001
EWB	H&N questions	*	0.016
	FWB; TOI; FACT-G; FACT-H&N	***	< 0.001
FWB	H&N questions; TOI; FACT-G; FACT-H&N	***	< 0.001
Additional concerns (H&N questions)	TOI; FACT-G; FACT-H&N	***	< 0.001
TOI	FACT-G; FACT-H&N	***	< 0.001
FACT-G	FACT- H&N	***	< 0.001
Correlation between Shame and Stigma Scale (SSS) domains (Spearman's Rho positive)			
Subscale	SSS		p
Shame with appearance	Regret	*	0.026
	Sense of stigma; regret; total score	***	< 0.001
Sense of stigma	Regret	**	0.003
	Speech/social concerns	**	0.002
	Total score	***	< 0.001
Regret	Total score	***	< 0.001
Speech/social concerns	Total score	***	< 0.001

Abbreviations: CI, confidence interval; FACT-G, Functional Assessment of Cancer Therapy: General; FACT-H&N, Functional Assessment of Cancer Therapy for Head and Neck Cancer; EWB, emotional well-being; FWB, functional well-being; PWB, physical well-being; SD, standard deviation; SSS, Shame and Stigma Scale; SWB, social and family well-being; TOI, Trial Outcome Index.

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

literature. The most relevant characteristics were the predominance in male patients, the average age around 60 years, low education, low socioeconomic status, and the most prominent profession was rural activity.^{3,4,24-26}

The relationship between head and neck cancer and smoking and alcoholism is well documented. Of the interviewed patients, 83.3% used tobacco and 66.6% alcohol, which is in agreement with other studies. In addition, patients had prolonged exposure to tobacco and alcohol with a mean of 36.6 years (± 14.78) and 31.1 years (± 13.7), respectively. These results were similar to those in the study by Santos et al.,³ who observed approximate results, with an average tobacco use of 30.7 years and alcohol of 31.1 years.^{4,6,26,27}

The location of head and neck tumors, in relation to prevalence, varies according to the literature approached. In the present study, oral cavity (28.6%), pharynx (26.3%), and larynx (26.3%) tumors prevailed.^{3,4,9,10,17,25,26} Squamous cell carcinoma was the predominant histological type, which is in agreement to other studies.^{4,8}

As for staging, 71.4% of the patients were in advanced stage (III and IV). Late diagnosis influences therapeutic choice, requiring a more aggressive approach. In addition, the symp-

tom are more intense and disabling, contributing to the deterioration of the patient's quality of life, as shown by the FACT-H&N results. For example, the H&N questions domain, which is related to tumor symptoms and treatment, presented worse results the more advanced the staging.^{10,17,24,26}

Another important factor that interferes with staging, quality of life and prognosis of the disease is the time between symptoms and the beginning of treatment, which in the current study showed a significant delay, with an average of 1 year and 4 months. And although the time between the first biopsy and the start of treatment was less significant, the average time was 6 months. The reasons for the delay between symptoms and the start of treatment may be related to the patient's lack of knowledge about the disease, difficulty in accessing the health system, and slow diagnosis and treatment processes, as described in other studies.²⁸

Regarding the therapy used in the interviewed patients, all received radiotherapy, and only 12 (28.6%) also underwent surgery, which can usually cause aesthetic changes, restriction of independence in daily activities, chewing difficulties, swallowing, speech, disorders of mood and anxiety. Radiotherapy has some advantages over surgery;

Table 7 Spearman correlations between the Functional Assessment of Cancer Therapy for Head and Neck Cancer domains with the Shame and Stigma Scale domains

Correlation between domains (Spearman's Rho negative)			
Subscale	SSS		<i>p</i>
PWB	Shame with appearance	*	0.013
	Regret7	*	0.036
	Speech/social concerns	***	< 0.001
	Total score	**	0.002
SWB	Shame with appearance	**	0.007
	Speech/social concerns	**	0.004
EWB	Shame with appearance; regret; total score	***	< 0.001
	Sense of stigma	**	0.001
	Speech/social concerns	**	0.002
FWB	Shame with appearance; sense of stigma; speech/social concerns; total score	***	< 0.001
	Regret	*	0.011
Additional concerns (H&N questions)	Speech/social concerns	**	0.006
TOI	Shame with appearance	**	0.002
	Sense of stigma	*	0.040
	Regret	*	0.025
	Speech/social concerns; total score	***	< 0.001
FACT-G	Shame with appearance; speech/social concerns; total score	***	< 0.001
	Sense of stigma	**	0.001
	Regret	*	0.021
FACT-H&N	Shame with appearance; speech/social concerns; total score	***	< 0.001
	Sense of stigma	*	0.014
	Regret	*	0.034

Abbreviations: FACT-G, Functional Assessment of Cancer Therapy: General; FACT-H&N, Functional Assessment of Cancer Therapy for Head and Neck Cancer; EWB, emotional well-being; FWB, functional well-being; PWB, physical well-being; SSS, Shame and Stigma Scale; SWB, social and family well-being; TOI, Trial Outcome Index.

**p* < 0.05

***p* < 0.01

****p* < 0.001

however, some patients have undesirable effects, such as oral mucositis, xerostomia, and loss of taste.^{10,25,29,30}

The result of the assessment of quality of life in patients with head and neck cancer submitted to radiotherapy through the FACT-H&N indicates similar points to another study that used the same instrument, but evaluated patients submitted mainly to surgical treatment. According to Nogueira et al.¹⁰, the domain with the worst result was also the H&N questions, with a proportional average of 56.0, similar to the present study, which was 57.8. However, there was a divergence regarding the best domain, which was the emotional well-being domain for them and, in this study, it was the social and family well-being domain. Regarding the overall value of FACT-H&N, in this study, it was higher 107 (± 22.9) against 96.6 (± 20.5), it cannot be stated that the predominant therapy is the reason for the difference, but

it would be interesting to further explore the differences in quality of life between groups of patients exposed exclusively to radiation and surgery.

In another study that monitored the quality of life of head and neck cancer patients throughout radiotherapy treatment, it showed a worsening in the global scales: TOI, FACT-G, and FACT-H&N. However, two weeks after the end of radiotherapy, there was an improvement in global scales values, showing that undesirable symptoms of radiotherapy such as mucositis and xerostomia generally have a more transient impact on patients' quality of life.³⁰

Generally, the disease itself, depending on the therapy employed, especially extensive and mutilating surgery, implies changes in body image and physical appearance, as well as basic functions, such as speaking and swallowing. Consequently, all of these factors often lead the patient to develop negative

Table 8 Comparison between caregiver and non-caregiver patients regarding the Functional Assessment of Cancer Therapy for Head and Neck Cancer responses

	Has no caregiver n = 25		Has caregiver n = 17		W	p-value	Rank-Biserial correlation
	Mean	SD	Mean	SD			
PWB	20.5	5.8	16.6	5.8	287.5	0.027	0.409
SWB	25.3	3.6	22.1	3.8	309.0	0.005	0.515
EWB	20.2	4.6	19.4	5.4	222.5	0.625	0.091
FWB	23.0	6.0	20.4	5.2	277.5	0.051	0.360
H&N questions	25.0	7.8	21.4	6.6	258.5	0.151	0.267
TOI	68.8	16.8	58.4	13.4	278.5	0.050	0.365
FACT-G	89.1	17.8	78.7	12.9	310.5	0.005	0.522
FACT-H&N	114.1	22.7	100.1	17.4	293.0	0.019	0.436

Abbreviations: EWB, emotional well-being; FWB, functional well-being; PWB, physical well-being; FACT-G, Functional Assessment of Cancer Therapy: General; FACT-H&N, Functional Assessment of Cancer Therapy for Head and Neck Cancer; FWB, functional well-being; SD, standard deviation; SWB, social and family well-being; TOI, Trial Outcome Index; W = comparison test statistic for independent non-parametric Man-Whitney samples. Note: significant *p*-value if less than or equal to 0.05; Rank-Biserial Correlation = effect size.

feelings, such as social isolation, depression, and stigma, which can be defined as a feeling of social disapproval. These feelings were assessed through the SSS instrument, which showed the feeling of regret as the most significant for patients, and stigma as the least important.^{12,20}

An important aspect of the results was the evaluation of the item appearance and shame of the SSS, which presented little significant result. Probably, this fact is related to the low rate of surgical intervention among the interviewed patients and, therefore, with less impact on body image.

Feelings related to appearance, shame, stigma, regret, and social isolation explored through the SSS correlated with the patients' quality of life, because global scales, TOI, and FACT-G presented lower values the more important these feelings were for the patient. So, the feelings related to the disease somehow also changed the perception the patients' quality of life.²⁰

Similar to other studies, caregivers of head and neck cancer patients are usually women and the patient's spouse, and often have help from another family member.^{16,17} In addition, this research also found that having someone to help with patient care decreases the caregiver burden, with better results on the Zarit scale.

According to Rigoni et al.,¹⁷ caregivers had a compromised quality of life, similar to that of the head and neck cancer patient, showing that not only the patient becomes ill, but also his/her caregiver. The burden suffered by the caregiver plays a relevant role in this aspect, as pointed out by Honório et al.,¹⁶ with the main altered functions in the caregiver's life being overload and routine change.

Generally, there is little concern for the caregiver of the head and neck cancer patient and yet this plays an important role in the patient's quality of life. Through this work, it was noticed that patients with decreased quality of life demanded more from the need to have a caregiver, besides the greater the dependence of the patient the more the caregiver felt burdened.

Conclusion

The quality of life of patients with head and neck cancer is directly related to the feelings experienced by the patient. In addition, the deterioration in the quality of life usually demands the need for a caregiver. Therefore, it is important to evaluate the interference of treatments on patients' quality of life and feelings, so that the therapeutic decision and follow-up are as optimized as possible for the patient.

Conflict of interests

The authors declare no conflict of interests.

References

- Cervenka BP, Rao S, Bewley AF. Head and Neck Cancer and the Elderly Patient. *Otolaryngol Clin North Am* 2018;51(04): 741–751. Doi: 10.1016/j.otc.2018.03.004
- Cohen N, Fedewa S, Chen AY. Epidemiology and Demographics of the Head and Neck Cancer Population. *Oral Maxillofac Surg Clin North Am* 2018;30(04):381–395. Doi: 10.1016/j.coms.2018.06.001
- Santos JF, Alves Mda S, Ferreira SMIL, de Sousa NSO, de Oliveira PS. Características dos pacientes com câncer atendidos em um ambulatório de cirurgia de cabeça e pescoço no interior da Bahia. *Rev.Saúde. Com* 2016;12:528–534
- de Sousa AR, Koury GVH, Badaranne EBL, Cavalcante Hde A, Araújo CNF. Perfil clínico-epidemiológico de pacientes com câncer de cabeça e pescoço em hospital de referência. *Rev Soc Bras Clin Med* 2016;14:129–132
- Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA) Estimativa 2020: incidência de câncer no Brasil. 2019. Rio de Janeiro- RJ. Disponível em: <https://www.inca.gov.br/sites/ufu.sti.inca.local/files/media/document/estimativa-2020-incidencia-de-cancer-no-brasil.pdf>
- Rettig EM, D'Souza G. Epidemiology of head and neck cancer. *Surg Oncol Clin N Am* 2015;24(03):379–396. Doi: 10.1016/j.soc.2015.03.001

- 7 Wang T-H, Hsia S-M, Shih Y-H, Shieh T-M. Association of Smoking, Alcohol Use, and Betel Quid Chewing with Epigenetic Aberrations in Cancers. *Int J Mol Sci* 2017;18(06):1210. Doi: 10.3390/ijms18061210
- 8 Galbiatti ALS, Padovani-Junior JA, Maníglia JV, Rodrigues CDS, Pavarino ÉC, Goloni-Bertollo EM. Head and neck cancer: causes, prevention and treatment. *Rev Bras Otorrinolaringol (Engl Ed)* 2013;79(02):239–247. Doi: 10.5935/1808-8694.20130041
- 9 Rocha BQC, Eneas L, Oliveira RG, Junqueira RB, Verner FS. Características epidemiológicas de pacientes portadores de neoplasias de cabeça e pescoço submetidos à radioterapia em Juiz de Fora – MG. *HU Revista* 2017;43:71–75
- 10 Nogueira T-E, Adorno M, Mendonça E, Leles C. Factors associated with the quality of life of subjects with facial disfigurement due to surgical treatment of head and neck cancer. *Med Oral Patol Oral Cir Bucal* 2018;23(02):e132–e137. Doi: 10.4317/medoral.22072
- 11 Richardson AE, Morton R, Broadbent E. Caregivers' Illness Perceptions Contribute to Quality of Life in Head and Neck Cancer Patients at Diagnosis. *J Psychosoc Oncol* 2015;33(04):414–432. Doi: 10.1080/07347332.2015.1046011
- 12 Pirola WE, Paiva BSR, Barroso EM, Kissane DW, Serrano CVMP, Paiva CE. Translation and cultural adaptation of the Shame and Stigma Scale (SSS) into Portuguese (Brazil) to evaluate patients with head and neck cancer. *Rev Bras Otorrinolaringol (Engl Ed)* 2017;83(06):697–704. Doi: 10.1016/j.bjorl.2016.10.005
- 13 Silveira A, Gonçalves J, Sequeira T, et al. [Head and neck cancer: health related quality of life assessment considering clinical and epidemiological perspectives]. *Rev Bras Epidemiol* 2012;15(01):38–48. Doi: 10.1590/S1415-790 × 2012000100004
- 14 Maciel CTV, Leite ICG, Soares TV. Câncer de laringe: um olhar sobre a qualidade de vida. *Rev Int Est Exp* 2010;2:126–134
- 15 Ribeiro AF, de Souza CA. O cuidador familiar de doentes com câncer. *Arq Ciênc Saúde* 2010;17:22–26
- 16 de Melo Honório I, de Almeida Marques da Cruz FO, Ferreira EB, et al. Ser cuidador de familiar com câncer de cabeça e pescoço. *Rev Bras Promoc Saúde* 2015;28:337–343. Doi: 10.5020/18061230.2015.p337
- 17 Rigoni L, Bruhn RF, De Cicco R, Kanda JL, Matos LL. Quality of life impairment in patients with head and neck cancer and their caregivers: a comparative study. *Rev Bras Otorrinolaringol (Engl Ed)* 2016;82(06):680–686. Doi: 10.1016/j.bjorl.2015.12.012
- 18 de Souza LR, Hanus JS, Dela Libera LB, et al. Sobrecarga no cuidado, estresse e impacto na qualidade de vida de cuidadores domiciliares assistidos na atenção básica. *Cad Saude Colet* 2015;23:140–149. Doi: 10.1590/1414-462 × 201500020063
- 19 Vartanian JG, Carvalho AL, Furia CLB, et al. Questionários para a avaliação de Qualidade de Vida em pacientes com câncer de cabeça e pescoço validados no Brasil. *Rev Bras Cir Cabeça Pescoço* 2007;36:108–115
- 20 Kissane DW, Patel SG, Baser RE, et al. Preliminary evaluation of the reliability and validity of the Shame and Stigma Scale in head and neck cancer. *Head Neck* 2013;35(02):172–183. Doi: 10.1002/hed.22943
- 21 Sczufca M. Brazilian version of the Burden Interview scale for the assessment of burden of care in carers of people with mental illnesses. *Br J Psychiatry* 2002;24:12–17. Doi: 10.1590/S1516-44462002000100006
- 22 Conselho Regional de Medicina do Estado de São Paulo (CREMESP) Cuidado Paliativo. 2008. São Paulo - SP. Disponível em: http://www.cremesp.org.br/library/modulos/publicacoes/pdf/livro_cuidado%20paliativo.pdf
- 23 Lau F, Downing GM, Lesperance M, Shaw J, Kuziemy C. Use of Palliative Performance Scale in end-of-life prognostication. *J Palliat Med* 2006;9(05):1066–1075. Doi: 10.1089/jpm.2006.9.1066
- 24 Almeida AF, Alves RC, Felix JD, Castro DS, Zandonade E, Rocha RM. Quality of Life in Patients Suffering from Upper Aerodigestive Tract Cancer at a University Hospital. *Rev Bras Cancerol* 2013;59:229–237
- 25 Melo Filho MR, Rocha BA, Pires MB, et al. Quality of life of patients with head and neck cancer. *Rev Bras Otorrinolaringol (Engl Ed)* 2013;79(01):82–88. Doi: 10.5935/1808-8694.20130014
- 26 Sommerfeld CE, Garcia Andrade M da G, Santiago SM, et al. Qualidade de vida em pacientes com câncer de cabeça e pescoço. *Rev bras cir cabeça pescoço* 2012;41:172–177
- 27 Almeida AA, Bandeira CM, Gonçalves AJ, Araújo AJ. Nicotine dependence and smoking habits in patients with head and neck cancer. *J Bras Pneumol* 2014;40(03):286–293. Doi: 10.1590/S1806-37132014000300012
- 28 Le Campion ACOV, Santos KCB, Carmo ES, et al. Characterization of diagnostic delay in oral and oropharyngeal cancer at two referral centers. *Cad Saude Colet* 2016;24:178–184. Doi: 10.1590/1414-462 × 201600020004
- 29 de Souza FRN, Barbosa Gde S, Prado Gda M, Schweitzer CM, Júnior EGJ. Qualidade de vida de pacientes submetidos à radioterapia para tratamento de lesões malignas de cabeça e pescoço. *Arch Health Invest* 2013;2:28–33
- 30 Franco P, Martini S, Di Muzio J, et al. Prospective assessment of oral mucositis and its impact on quality of life and patient-reported outcomes during radiotherapy for head and neck cancer. *Med Oncol* 2017;34(05):81. Doi: 10.1007/s12032-017-0950-1