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

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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

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

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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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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 (UNIFAFE) 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.\textsuperscript{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.\textsuperscript{31–23}

**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 Man-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 Table 1 and 2. There was a predominance of males, represented by 78.6% of the patients, the average age was 60.3 years (\( \pm 10.7 \)), 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 (\( \pm 1.7 \)).

The time elapsed between the 1st symptom and the beginning of treatment was on average 1 year and 4 months (\( \pm 1.5 \)) with 95% CI (0.9–1.8). And the time interval between the 1st biopsy and treatment was 6 months on average, with SD (\( \pm 8.0 \)) 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 (\( \pm 14.9 \)), 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 (\( \pm 1.0 \)) 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 (\( \pm 2.5 \)).

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 n = 42 | Caregiver n = 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     | 11.8    |
| Single             | 8     | 19.0    | 3     | 17.7    |
| 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     | 0       |
| Evangelical        | 6     | 14.3    | 2     | 11.8    |
| Educational level  |       |         |       |         |
| Illiterate         | 4     | 9.5     | 0     | 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     | 0       |
| Profession         |       |         |       |         |
| Rural activity     | 10    | 24.4    | 1     | 5.9     |
| Cleaning assistant | 2     | 4.7     | 0     | 0       |
| Hairdresser        | 2     | 4.7     | 0     | 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     | 0       |
| Driver             | 4     | 9.7     | 1     | 5.9     |
| Baker              | 2     | 4.7     | 0     | 0       |
| Bricklayer         | 2     | 4.7     | 0     | 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              |                   |                      |       |    |         |
| Oropharynx           |                   |                      |       |    |         |
| Amygdala             | 5                  | 71.4                 | 11.9  |    |         |
| Tongue base          | 1                  | 14.3                 | 2.4   |    |         |
| Not localizable      | 1                  | 14.3                 | 2.4   |    |         |
| 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  | 11.9    |
|                        |                  | 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     | 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 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   | 17.8  | 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.

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 < 0.05, 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
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.\textsuperscript{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 ($\pm$ 14.78) and 31.1 years ($\pm$ 13.7), respectively. These results were similar to those in the study by Santos et al.,\textsuperscript{3} who observed approximate results, with an average tobacco use of 30.7 years and alcohol of 31.1 years.\textsuperscript{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.\textsuperscript{3,4,9,10,17,25,26} Squamous cell carcinoma was the predominant histological type, which is in agreement to other studies.\textsuperscript{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 symptoms 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.\textsuperscript{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.\textsuperscript{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 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 |
| | 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
however, some patients have undesirable effects, such as oral mucositis, xerostomia, and loss of taste.\textsuperscript{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.\textsuperscript{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 (\textpm 22.9) against 96.6 (\textpm 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.\textsuperscript{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 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) | SSS | \( p \) |
|------------------------------------------------------|-----|-----|
| PWB                                                  | Shame with appearance | *   | 0.013 |
|                                                     | Regret              | *   | 0.036 |
|                                                     | Speech/social concerns | *** | \(< 0.001 \) |
|                                                     | Total score         | **  | 0.002 |
| SWB                                                  | Shame with appearance | **  | 0.007 |
|                                                     | Speech/social concerns | **  | 0.004 |
| EWBN                                                 | 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.

\( ^* p < 0.05 \)

\( ^{**} p < 0.01 \)

\( ^{***} p < 0.001 \)
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.

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