Clinical Information and its Relationship with the Quality of Life of Patients with Head and Neck Cancer

Informação Clínica e sua Relação com a Qualidade de Vida em Pacientes com Câncer de Cabeça e Pescoço

La Información Clínica y su Relación con la Calidad de Vida en Pacientes con Cáncer de Cabeza y Cuello

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ABSTRACT

Introduction: Head and neck cancer treatment have a profound impact on patients' quality of life due to physical, psychological, aesthetic, social and emotional sequelae. The information provided by health professionals in the continuum of the clinical process of these patients is seen as a key factor of quality health care and with multiple benefits in their Quality of Life. **Objective:** To investigate the perception of patients with head and neck cancer in relation to the information provided and the existence of a correlation with their quality of life. **Method**: Cross-sectional study with a sample of 38 head and neck cancer patients, selected for convenience from a potential sample of 347 patients. The EORTC QLQ-C30 questionnaire and the EORTC QLQ-INFO25 questionnaire were applied 2 to 4 months after the end of the treatments. All calculations were performed with SPSS, version 24, using descriptive statistics for sample characterization and nonparametric tests to evaluate the possible correlation between the variables under study. **Results:** Patients' perception of the information provided, and their quality of life is satisfactory and there is a correlation between them. **Conclusion**: The data obtained concur with those reported in the literature being possible to conclude that the information provided by health professionals is important for patients' Quality of Life. Knowing the necessity these patients have of information allows to adjust the strategies of health professionals for a better healthcare and, consequently, their quality of life.
Key words: head and neck neoplasms; delivery of health care; patient satisfaction; quality of life.

RESUMO

Introdução: O tratamento do câncer de cabeça e pescoço tem grande impacto na qualidade de vida dos pacientes pelas sequelas físicas, psicológicas, estéticas, sociais e emocionais. A informação prestada pelos profissionais de saúde no *continuum* do processo clínico desses pacientes é tida como um fator-chave dos cuidados de saúde de qualidade e com múltiplos benefícios na sua qualidade de vida. **Objetivo:** Averiguar a percepção dos pacientes com câncer de cabeça e pescoço relativamente à informação prestada e a existência de correlação com a sua qualidade de vida. **Método:** Estudo transversal com amostra de 38 pacientes com câncer de cabeça e pescoço, selecionados por conveniência de amostra potencial de 347 pacientes. Recorreram-se aos questionários EORTC QLQ-C30 e EORTC QLQ-INFO25, aplicados dois a quatro meses após o término das terapias oncológicas. Todos os cálculos foram efetuados com recurso ao SPSS, versão 24, utilizando-se a estatística descritiva para caracterização da amostra e testes não paramétricos para avaliar a possível correlação entre as variáveis em estudo. **Resultados:** A percepção dos pacientes, relativa à informação prestada e à sua qualidade de vida, é razoável, existindo correlação entre ambas. **Conclusão:** Os dados obtidos vão ao encontro dos referidos na literatura, podendo-se aferir que a informação prestada pelos profissionais de saúde é importante para a qualidade de vida dos pacientes. O conhecimento das necessidades informativas permite adequar as estratégias dos profissionais de saúde no sentido de uma melhor prestação de cuidados de saúde e, consequentemente, da qualidade de vida dos pacientes.
Palavras-chave: neoplasias de cabeça e pescoço; atenção à saúde; satisfação do paciente; qualidade de vida.

RESUMEN

Introducción: El tratamiento del cáncer de cabeza y cuello tiene un profundo impacto en la calidad de vida de los pacientes debido a las secuelas físicas, psicológicas, estéticas, sociales y emocionales. La información que brindan los profesionales de la salud en el continuo del proceso clínico de estos pacientes es vista como un factor clave en la atención de la calidad de la salud y con múltiples beneficios en su calidad de vida. **Objetivo:** Investigar la percepción de los pacientes con cáncer de cabeza y cuello en relación a la información brindada y la existencia de una correlación con su calidad de vida. **Método**: Estudio transversal con una muestra de 38 pacientes con cáncer de cabeza y cuello, seleccionados por conveniencia de una muestra potencial de 347 pacientes. Se utilizó los cuestionarios EORTC QLQ-C30 y EORTC QLQ-INFO25, que se aplicaron de 2 a 4 meses después de finalizar las terapias oncológicas. Todos los cálculos se realizaron en SPSS, versión 24, utilizando estadística descriptiva para caracterizar la muestra y pruebas no paramétricas para evaluar la posible correlación entre las variables en estudio. **Resultados**: La percepción de los pacientes sobre la información proporcionada y su calidad de vida es razonable, con correlación entre ambos. **Conclusión**: Los datos obtenidos están en línea con los reportados en la literatura, y se puede verificar que la información brindada por los profesionales de la salud es importante para la calidad de vida de los pacientes. El conocimiento de las necesidades de información permite ajustar las estrategias de los profesionales de la salud en el sentido de una mejor prestación asistencial y, en consecuencia, de la Calidad de Vida de los pacientes.
Palabras clave: neoplasias de cabeza y cuello; atención a la salud; satisfacción del paciente; calidad de vida.

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INTRODUCTION

Currently, the oncologic disease is a public health problem with clear impact on the families, economy and society[1].

Medicine advances led to early phase diagnosis and less invasive treatment options, minimizing sequelae and increasing patients' survivorship. However, because of the anatomic complexity and functional importance of the head and neck region, the patients with this pathology have to cope with multiple challenges at diagnosis, pre and post-treatment[2] which determine their quality-of-life in addition to inherent problems of every oncologic disease. As such, its evaluation is imperative in order to optimize decision making and patient-centered[2] care that match their individual needs, enabling them with the required tools for an autonomous life[3].

Thus, the clinical information given to the patient in the *continuum* of its diagnosis and treatment should be seen as one of the pillars of quality health care, making it an active agent of its clinical process. Several authors[4-6] quote the importance of giving a correct and patient-centered clinical information as enhancer of several benefits that foster a better quality of life of the patient.

The evaluation of the information provided ensures healthcare professionals and services to know the patient's actual needs and check whether their practice meets these demands, potentially contributing for adjustments and definition of strategies to improve the health outcomes and eventually promoting equity and consistent access to healthcare.

In this perspective, this study aims to investigate the perceptions that patients with head and neck cancer (HNC) in follow up at "*Instituto Português de Oncologia de Lisboa Francisco Gentil* (IPOLFG)" have about the information provided to them in the course of its clinical process and a possible correlation with their quality-of-life.

This investigation is important since the correct information the patient receives allows him, among other aspects, to have tools that make him an active agent of its clinical process and at the same time, improve the clinical practice; the patient should be the center of the care for continuous improvement of the practice.

METHOD

A cross-sectional, observational study was developed, the data were collected from two to four months after the conclusion of the protocol of oncologic therapies.

The approval by the European Organization for Research and Treatment of Cancer (EORTC) was required to utilize the EORTC QLQ-C30 questionnaires of quality-of-life and perception of the information EORTC QLQ-INFO25 further to the approval by the Institutional Review Board and by "*Unidade de Investigação Clínica*" of IPOLFG, study code UIC-1240.

The population consisted of patients with HNC submitted to surgery and complementary therapies – radiotherapy (RT) or RT + chemotherapy (CT) – at IPOLFG between September 2018 and August 2019.

The sample was formed by convenience according to the inclusion criteria: main cancer diagnosis in any part of the head and neck and in any stage; patients with HNC >18 years of age; patients submitted for the first time to surgical procedure for this clinical condition with cervical lymphadenectomy and/or RT or RT + CT; and patients between two and four months after the end of the treatment and complementary therapies. The exclusion criteria were: patients submitted to conserving surgery, patients submitted to surgical intervention alone without cervical lymphadenectomy, patients with psychological and cognitive alterations and/or with language impairments hindering the comprehension of the study and filling forms and illiterate patients.

In all, a total of 347 patients were listed after consulting the services of Head and Neck Surgery, of Otorhinolaryngology and Physical Medicine and Rehabilitation of IPOLFG. Upon review of their clinical charts and applying the inclusion criteria, a potential sample of 54 individuals was reached. Of these, five died, three failed to attend the encounter with the investigator, one, the clinical condition has been aggravated which led to hospital admission, four were illiterate, two were foreigners and did not understand Portuguese and one had reduced visual acuity. Eventually, 38 patients with HNC were eligible (Figure 1).

The patients selected were contacted by telephone to schedule an encounter with the investigator when full information about the study were offered and an informed consent form was signed. Ethical issues were complied with throughout the study, patients' anonymity and confidentiality of the data were secured.

The characterization variables were gender, age, marital status, education, occupation, clinical diagnosis, recurring clinical condition, remote metastases and options of oncologic treatment. A form was created to collect these variables based in the data reported by the patients and found in their chart.

The dependent variables were evaluated with the content of the questionnaire of quality-of-life EORTC QLQ-C30 (variable: global health status/quality of life – GHS/QoL – determined by scale with the same name) and of perception of information EORTC QLQ-INFO25 (variables: information about the disease, medical tests,
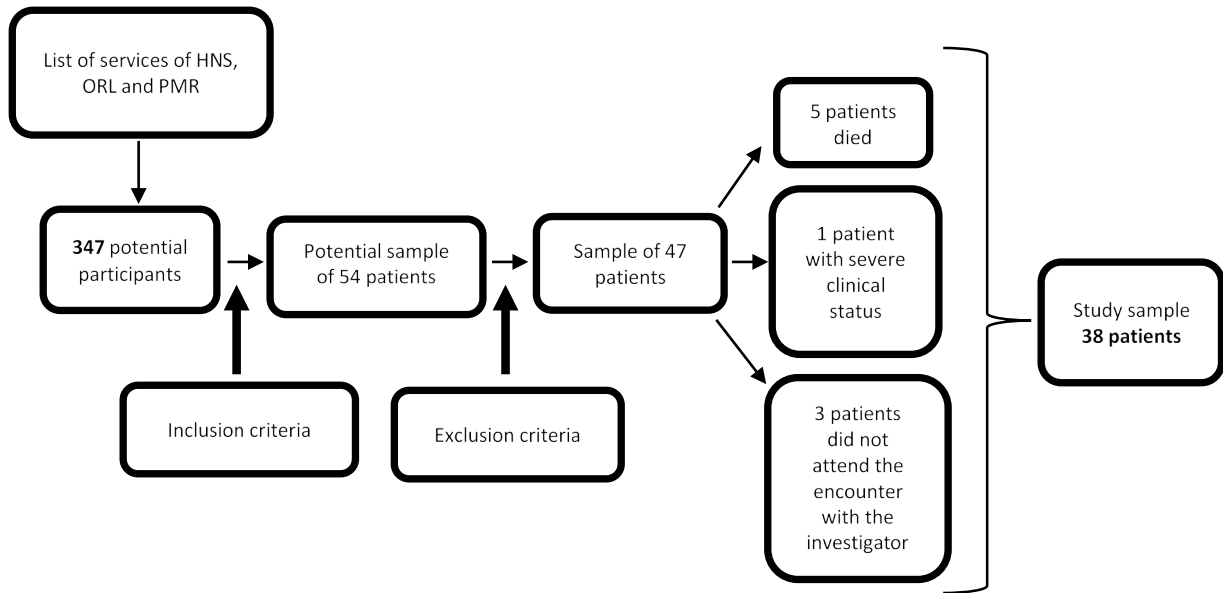
Figure 1. Selection of the study sample

Captions: HNS = head and neck surgery; ORL = otorhinolaryngology; PMR = physical medicine and rehabilitation.

treatments and other services, how the information was given and satisfaction with it), both validated for the Portuguese population[7-9].

The questionnaire QLQ-C30 developed by EORTC is a specific instrument for oncologic patients with domains common to different types of malignant neoplasms and their treatments[10], ensuring the evaluation of the perception of its quality-of-life. According to Pimentel[11], it is the most utilized questionnaire in Europe and widely adopted worldwide, a self-administered, clear, short, easily applicable questionnaire and simple to fill. The questionnaire of quality-of-life EORTC QLQ-C30 as concluded by Arraras et al.[4] and Bozec et al.[6], is an instrument validated and translated in several countries, widely applied in interventions of clinical trials and individual monitoring[11]. The translation and validation for the Portuguese population was made by Ferreira[8] and Pais-Ribeiro et al.[9] and approved by EORTC, one of the most utilized questionnaires in studies of this area and in the Portuguese population.

EORTC QLQ-C30 is a modular approach questionnaire to assess the most relevant aspects for great part of oncologic diseases, however, because of the specificities of each cancer, specific modules must be utilized for more accurate evaluation[11]. For the Portuguese population, some modules were translated and validated, among them the questionnaire EORTC QLQ-INFO25, which evaluates the perception the oncologic patient has about the volume of information he receives in the course of the clinical process since the diagnosis until the end of the treatment.

According to Arraras et al.[5], this instrument can be used in different situations and timing as in routine clinical practice, investigation, at the evaluation of the system of disclosing the information of a department/oncologic service, both nationally and internationally. Arraras et al.[4] validated the questionnaire internationally and Matos[7] translated and validated the questionnaire for the Portuguese population in the version EORTC QLQ-INFO26, which eventually resulted in the final version EORTC QLQ-INFO25.

The final version was validated, consented and approved by EORTC[12,13]. It is an easy-to-understand 25-items short instrument, preferentially auto filled and applied together with EORTC QLQ-C30[7].

The global score of this questionnaire ranges between 0 and 100, the higher values correspond to large amount of information received, wish to receive more information and more satisfaction of the patient[3].

Matos[7] reinforces that, further to the global score, the questionnaire of perception of the information EORTC QLQ-INFO25 allows direct comparison among multi-items scales, higher scores mean higher level of information.

Data collection occurred between April 15 and July 26, 2019.

Statistical Package for the Social Sciences (SPSS), version 24 was utilized for descriptive statistics to characterize the sample and analyze the data, and inferential statistics to investigate correlations. The tests of hypothesis were determined for level of significance of 5% and confidence intervals of 95%.

RESULTS

The sample consisted of 38 individuals (35 males and three females), with mean age of 60,658±9,979 years, mostly married (57.9% of the sample).

The majority of the study sample used tobacco (92.1%) and alcohol (78.9%) and the human papilloma virus (HPV) was detected in only 10.5%.

It was found that 31.6% of the sample have completed high-school; great part of the participants were retired (57.9%), 26.3% were active and the remaining in other jobs (Table 1).

Based in the clinical data of the sample (Table 2), larynx tumor was the most frequent (60.5% of the sample). HNC was diagnosed as primary tumor in 89.5% of the sample, with remote metastasis in 15.8% of the cases.

Surgery combined with complementary therapies was adopted in 94.8% of the sample.

PERCEPTION OF THE QUALITY OF LIFE (EORTC QLQ-C30)

The median of the score GHS/QoL was 66.667% (Table 3), considered moderate.

The Cronbach's Alpha internal reliability coefficient was 0.904.

PERCEPTION OF THE INFORMATION RECEIVED (EORTC QLQ-INFO25)

The internal consistency was measured for each one of the scales and Cronbach's Alpha coefficient was >0.70 for all of them.

The scores of the scales *information about the disease; about medical tests; about the treatment; about self-care; satisfaction with the information;* and *utility of the information* presented medians greater than 50%. In the scale *information about different health care locations*, the median of the scores was 33.333%, which indicates that the patients received insufficient information about this subject; the medians of the score of the scale *written*

Table 1. Variables of sociodemographic characterization of the study sample

Variable	Categories	Absolute frequency	Relative frequency	Descriptive statistic (n=38)
Gender	Male	35	92.1%	
	Female	3	7.9%	
Age	Years			Median: 62,000 Mean: 60,658 years Standard deviation: 9,979 years Min.-Max.: 38,000- 82,000
Marital Status	Single	6	15.8%	
	Married	22	57.9%	
	Divorced	3	7.9%	
	Widow/Widower	1	2.6%	
	Stable union	6	15.8%	
Tobacco use	No	3	7.9%	
	Yes	35	92.1%	
Alcohol use	No	8	21.1%	
	Yes	30	78.9%	
Human Papillomavirus	No	34	89.5%	
	Yes	4	10.5%	
Education	Elementary	11	28.9%	
	Pre-high school	9	23.7%	
	High school	12	31.6%	
	University	6	15.8%	
Occupation	Active	10	26.3%	
	Retired	22	57.9%	
	Other	6	15.8%	

Table 2. Variables of clinical characterization of the study sample

Variable	Categories	Absolute frequency	Relative frequency	Descriptive statistic (n=38)
Clinical diagnosis	Larynx tumor	23	60.5%	
	Oropharynx tumor (base of the tongue, amygdala and adenoids)	5	13,2%	
	Hypopharynx tumor	3	7.9%	
	Tumor of the oral cavity and mobile tongue	3	7.9%	
	Tumor of salivary glands	2	5.3%	
	Bone, maxillofacial and odontogenic tumor	1	2.6%	
Recurring clinical condition	Tumor of the ear	1	2.6%	
	No	34	89.5%	
Remote metastasis	Yes	4	10.5%	
	No	32	84.2%	
Treatment options	Yes	6	15.8%	
	Surgery	2	5.3%	
	Surgery + RT	16	42.1%	
	Surgery + RT + CT	18	47.4%	
	RT+ CT + surgery	2	5.3%	

Captions: RT = radiotherapy; CT = chemotherapy.

information was 100%, 0.000% for the scale *information in CD/cassette/video*, and for the scale *wish to receive more information*, respectively and 100% for the score of the scale *wish to receive less information*. Based in this, it was found that the patients received written information, but it wasn't offered to them the option of receiving in digital format. For the amount of information, it has been revealed that most of the patients did not wish to have received less information about their clinical process and they expressed the wish of receiving more clarification (Table 3).

The median of the global score of the questionnaire was 55.324%, although positive was close to upper limit of positivity of 50%, suggesting that the information provided to the patient in the course of its clinical process is correct, however, can be improved in regard to the amount and how it is provided.

CORRELATION OF THE SCALES OF EORTC QLQ-INFO25 WITH THE SCORE GHS/QOL OF EORTC QLQ-C30

With Spearman's correlation (Table 4), it was concluded that there was statistically significant correlation between the score GHS/QoL and the *information about medical tests* (R=0.323, p<0.05) and the *satisfaction with the information* (R=0.456, p<0.01). These results indicate that who has more information about medical exams and who is satisfied with the information received have better quality-of-life.

The value of *p*>0.05 in the threshold of significance (R=0.311, p<0.10) suggests a possible correlation between the score of GHS/QoL and the global score of the questionnaire of perception of information that may be considered moderate according to Spearman's coefficient. In global terms, who received more information appears to have better quality-of-life.

DISCUSSION

Although the numbers reached by the present study are slightly greater than the literature, this is a pathology most common in males and in the sixth decade of life. Bozec et al.[6] found that it was more frequent in males (75% of the sample) younger than 65 years old. In Portugal[14], most of the individuals were males with mean age of 58.1 years.

Table 3. Descriptive statistic and internal consistency of the score GHS/QoL of the questionnaire of quality-of-life EORTC QLQ-C30 and of the questionnaire of perception of information EORTC QLQ-INFO25 (different scales and global score), in the period of 2-4 months after the end of the treatment

Score	Descriptive statistics	Cronbach's Alpha
GHS/QoL	Median: 66.667 Mean: 66.008 Standard deviation: 22.123 Min.-Max.: 16.67- 100.0	0.904
Information about the disease	Median: 62.500 Mean: 60.746 Standard deviation: 26.770 Min.-Max.: 8.33 - 100.00	0.873
Information about medical tests	Median: 66.667 Mean: 64.912 Standard deviation: 26.157 Min.-Max.: 0.00 - 100.00	0.875
Information about the treatment	Median: 58.333 Mean: 58.187 Standard deviation: 25.792 Min.- Max.: 11.11- 100.00	0.895
Information about other services	Median: 45.8333 Mean: 46.272 Standard deviation: 25.090 Min.- Max.: 0.00- 100.00	0.716
Information about different care clinics	Median: 33.333 Mean: 42.983 Standard deviation: 35.436 Min.- Max.: 0.00- 100.0	*
Information about self-care	Median: 66.667 Mean: 60.526 Standard deviation: 31.817 Min.- Max.: 0.00- 100.00	*
Written information	Median: 100.000 Mean: 57.895 Standard deviation: 50.036 Min.- Max.: 0.00 e 100.00	*
Information in CD/Cassette/Video	Median: 0.000 Mean: 7.895 Standard deviation: 27.328 Min.- Max.: 0.00 e 100.00	*
Satisfaction with the information	Median: 66.667 Mean: 67.544 Standard deviation: 28.461 Min.- Max.: 0.00- 100.00	*
Wish to receive more information	Median: 0.000 Mean: 28.947 Standard deviation: 45.961 Min.- Max.: 0.00 e 100.00	*
Wish to receive less information	Median: 100.000 Mean: 94.737 Standard deviation: 22.629 Min.- Max.: 0.00 e 100.00	*

Table 3. continuation

Score	Descriptive statistics	Cronbach's Alpha
Utility of the information	Median: 66.667 Mean: 74.561 Standard deviation: 26.206 Min.- Max.: 33.33- 100.00	*
Global **EORTC QLQ-INFO25**	Median: 55.324 Mean: 55.434 Standard deviation: 16.162 Min.- Max.: 22.69- 91.67	0.733

Captions: GHS/QoL = Global Health Status/Quality of Life; EORTC = European Organization for Research and Treatment of Cancer; QLQ = questionnaires of quality of life; Min. = minimum; Max = maximum.
(*) Cronbach's Alpha was not calculated.

Note: 0.00% − Poor; 100.00% − Very good. Except in the scales of written information and the information in CD/Video/Cassette, when 0% did not receive the information and 100% did and in those for wish to receive more and less information where 0% is yes and 100%, no.

To a great extent, the study sample consisted of married individuals (57.9%), similar to what was found in the study of Estêvão et al.[14], where it was confirmed that married individuals were a great portion of the sample (62.2%). Family structure, although barely referred in the literature when associated with this type of tumor[14], is an important aspect because strong family support can impact the adherence to the treatments, respect medications schedule and control of other comorbidities[14]. This concept was corroborated along the study because the patients without family support had worse survivorship rates[14].

Education level of the patients of the study sample is higher than referred in the literature[6,14], which indicates that this type of cancer is not associated with poor education and low socioeconomic conditions. Several authors[14-16] indicated that low education level should be considered most of all when associated with tobacco and alcohol use, leading to a twofold higher risk of developing HNC[16]. Despite some variation among countries, large portion of the patients in Portugal (82.5%) completed the elementary school and illiteracy is 6.7%[14]. The present study found that 31.6% of the sample had completed high school, 15.8%, completed university, of which some of them attended graduate courses.

This group of patients can also be defined by their professional activity because apparently the exposure at the job may account for the appearance and development of this pathology. Only the work status classified as actives, retired and other (unemployed or temporary off-job) was investigated in this study. Active employed patients represented 26.3% of the sample, slightly below the range from 30.8%[14] to 39.0%[6] found in the literature. Great part of the study sample consisted of retired (57.9%), above the level found by Estêvão et al.[14] (33.1%). These authors[14] have also concluded that 36.12% of the patients

Table 4. Spearman's Correlation between the questionnaire of perception of information EORTC QLQ-INFO25 and the score GHS/QoL of the questionnaire of quality-of -life EORTC QLQ-C30

Score	Score GHS/QoL
Information about the disease	0.175 Value of p=0.295
Information about medical tests	0.323** Value of p=0.048
Information about the treatments	0.209 Value of p=0.209
Information about other services	0.189 Value of p=0.256
Information about different locations where care was provided	0.265 Value of p=0.108
Information about self-care	0.098 Value of p=0.559
Written information	0.161 Value of p=0.334
Information in CD/Cassette/ Video	-0.036 Value of p=0.829
Satisfaction with the information	0.456* Value of p=0.004
Receive more information	0.121 Value of p=0.468
Receive less information	-0.263 Value of p=0.111
Utility of the information	0.214 Value of p=0.196
Global **EORTC QLQ- INFO25**	0.311*** Value of p=0.058

Captions: GHS/QoL = Global Health Status/Quality of Life; EORTC = European Organisation for Research and Treatment of Cancer; QLQ = questionnaires of quality of life.
(*) The correlation is statistically significant for p<0.01.
(**) The correlation is statistically significant for p<0.05.
(***) The correlation is statistically significant for p<0.10.

were recipients of disease/impairment or unemployment benefits in contrast with the present study which found only 15.8% of the patients sharing this same condition.

It appears to be a consensus that tobacco and alcohol use are the major risk factors of HNC. The study sample was mostly formed by smokers (92.1%) and alcohol users (78.9%), similar to the existing literature where 91.2% of the individuals used alcohol and 81.00%, tobacco (70% are current smokers and 11.0% ex-smokers)[14].

HPV is another pathogenesis factor for HNC to be considered. Comparatively with the current literature, the virus-related infection, as found in the present study, was detected in 10.5% of the sample, lower than reported, although an important signal. This infection accounts for 17-56% of the cancers of oropharynx in developed countries and for 13% in the less developed[17]. Other studies[18,19] report that in the United States of America, this association refers to 40%-80% of oropharynx cancers.

Great number of the cases were larynx tumors (60.5% of the sample) followed by oropharynx (13.2%), hypopharynx (7.9%) and oral cavity and tongue (7.9%) while analyzing the clinical characteristics. These results concur with the expected and quite similar to a study carried out in Portugal[14], where the incidence showed the same numbers but in different percentages. Data available at the "*Registro Oncológico Nacional (RON)*"[20], for 2009 showed this same finding, where larynx tumor is the most incident in Portugal for both men and women. In contrast, the International Agency for Research on Cancer (IARC)[21] concluded that in Portugal in 2018, the most frequent HNC was in the lip/oral cavity and larynx ranked second.

Patients with HNC have high level of new primary tumors, relapses and synchronous tumor or metastases of the upper aerodigestive tract strongly related to the tobacco and alcohol-induced carcinogenetic molecular mechanisms[15]. The scenario expected for this study did not materialize as most of the patients did not relapse or presented remote metastasis, which can be justified by better awareness of the population with early diagnosis and possible timely referral for specialized hospitals. Estêvão et al.[14] affirm that the motives for more advanced stages of the disease found in their study sample are the delay in seeking medical care and prompt referral. Nearly 50% of the individuals with advanced stages of the disease will likely relapse within two years after the treatment as the literature refers and that 2%-10% of the patients will be diagnosed with synchronous tumors in the head and neck[15]. The risk of the second tumor in the digestive tract is four-fold higher in smokers than in non-smokers or ex-smokers, with low relapse of HNC associated with positive HPV[15].

Treatment options are based in the clinical evaluation, tumor staging, comorbidities and overall condition of the patient[22] and experience of the physician[23]. In the study sample, 94.8% of the patients were submitted to surgery with RT and/or CT, however, the discussion of these data is difficult because it has nuances associated with the clinical characteristics of the sample. However, in despite of medical advances in investigating other modalities, surgery, RT and CT are primordial in these clinical cases, it is known that 50%-70% of the patients receive RT alone or in combination with surgery and/or CT[24].

According to EORTC QLQ-INFO25, one of the forms of interpretation of the values obtained is to compare with reference numbers of the questionnaire of quality-of-life EORTC QLQ-C30 determined by the organization. However, the reference values utilized patients in the pre-treatment period as baseline who were not submitted to any surgical or therapeutic approach[25].

In relation to the scale GHS/QoL for patients with HNC of both genders and for all age ranges, EORTC indicates mean score of 64.1 and median of 66.7[26]. Comparing the numbers calculated with the reference, the median were similar, with a slight increase of the mean score of the present study. In other studies with patients with HNC, it was revealed that after the oncologic treatments, the score of the scale *global health status/quality-of-life* had a mean value of 57.9[27] and 61.0[6], both below this study. They evaluated the quality-of-life of patients in the pre-treatment period, which allowed to verify that there were no relevant changes in the perception of the quality-of-life between the two periods, similar to what other authors have concluded[28,29]. Comparing the numbers of the present study with the studies aforementioned, the patients have a better perception of their GHS/QoL, but as it was not evaluated in the period before the treatments, it is not possible to evaluate whether there was deterioration. In view of the conclusions of other studies, it is believed that the perception remains quite identical in the two periods, which eventually concurs with EORTC reference values.

The analysis of the internal consistency concurs with other studies which utilized this measurement instrument for patients with HNC[6,27], whose values are 0.88-0.95.

The evaluation of the internal consistency of the scales and the global score of the questionnaire of perception of the information EORTC QLQ-INFO25 showed a Cronbach's alpha coefficient of >0.70, considered a good internal consistency[6]. Similar data were encountered in studies which enrolled only patients with HNC[6,27] and in studies which included different oncologic pathologies[4,30-32].

While analyzing the patients' perception of the information within two-to-four months after the end of the treatment, it was reached a global score of the

questionnaire of perception of information EORTC QLQ-INFO25 of 55.324 (median), with mean of 55.434±16.162, which can be considered a reasonable result. Lower results were encountered in studies with patients with HNC whose global scores in the range from 37.2 and 42.5[6,27], as well as in studies with different oncologic pathologies whose global score was within 43.8[4] and 45.9[10].

The studies about information in patients with HNC[6,27] always address, at least, two moments of evaluation (before and after the treatment) appraising the difference of their perception of information. For comparison with the current study, only data of post-treatment of these studies were obtained, collected in different moments than the present study.

It has been confirmed that they have much information about the disease, medical tests, treatments, mechanisms of self-care and that they were satisfied with the information they received, being quite useful in their perspective. In contrast, the patients affirmed they have received some information about other services and different health care clinics, contrary to the data obtained in another study[6]. The written information was handed over to more than half of the sample, most of them reported they did not receive in digital format. Regardless of the scores indicating a quite fair perception of the information, in fact, the patients reported they wished to have more information, and as expected, they did not wish to receive less information.

Comparing the mean scores of the scales of the questionnaire of perception of information EORTC QLQ-INFO25 with the referenced studies[6,27], it was found that the present sample had higher scores for all the parameters evaluated. Although improvements in providing the information still need to be made, the health care givers following up the patients with this pathology have considered their necessity for information.

It was possible to find that only some correlation exist among the score of GHS/QoL and the scales and global score of the questionnaire of perception of the information EORTC QLQ-INFO25, similar to what was reported by Bozec et al.[6] and Arraras et al.[4], who concluded that it was probable, because each one of these instruments evaluates different concepts. It was found that there is correlation among the information about medical exams and the perception of quality-of-life and among the latter and satisfaction with the information received. It was also detected a suggestive possible correlation among the amount of information received and the perception the patient has about quality-of-life. This happens because the patients well informed about the medical exams to be performed and the results are

more able to better handle and control their clinical status and manage the disease choosing the better strategies to cope, minimizing the discomfort and promoting the well-being, which necessarily contributes for a better perception of the quality-of-life[33]. Therefore, satisfaction with the information received may indicate that health professionals succeeded in meeting the patients' needs of information, helping them to understand the nature, the extent and prognosis of the disease, potential outcome of the treatment and how to deal with the changes the clinical condition brought into their lives and of those who live with them.

The small size of the sample is a limitation of the study, it is the result of meeting the schedules (a scholar study) and the long time taken by the "*Unidade de Investigação Clínica*" and the Institutional Review Board of IPOLFG to approve the study. Even with a small sample by convenience, the results are innovative and important for the Portuguese clinical practice, in concurrence with the international literature. Another limitation is its cross-sectional approach which impedes the comparison of the results with the results of other steps of the patients' clinical process. Lastly, the memory bias, given that the questionnaire of perception of information EORTC QLQ-INFO25 evaluates the perception of the information the patient has at a certain moment of its clinical process.

CONCLUSION

In addition to the current population profile of this disease, it was possible to find that these patients have a reasonable perception of the quantity of the information given to them. However, improvements need to be made in diagnosis and medical tests, treatments, other services and mechanisms of self-care. Still, the information provided and the satisfaction with it is associated with the quality-of-life of these patients.

These data are important for clinical practice because they allow health caregivers to develop strategies of surveillance, awareness campaigns and/or screening of a specific population, promoting better health outcomes. In addition, while disclosing information about different areas, the perception and satisfaction of these professionals are encouraged, giving them opportunities to develop strategies that meet the needs and interests of the patients ensuring that they have the correct information. The changes in clinical practice that potentially may result from this knowledge ensure equity and improved access to healthcare and quality in health.

This understanding can be beneficial for health services since well-informed patients will possibly require

less medical care, reducing the number of consultations and avoidable hospitalizations, which will eventually cut health costs.

CONTRIBUTIONS

All the authors contributed to the study design/conception, acquisition, analysis and interpretation of the data, wording and critical review. They approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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