

## ORAL CANCER: VOICE AND QUALITY OF LIFE AFTER MUTILATION

Câncer bucal: voz e qualidade de vida pós mutilação

Cáncer oral: voz y calidad de vida después de la mutilación

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### ABSTRACT

**Objective:** to investigate the impact of oral cancer deformity on oral communication and the quality of life of adults and the elderly. **Methods:** descriptive, cross-sectional observational study with a mixed approach. Sample of 41 patients undergoing surgery to remove oral cancer, resulting in mutilation and verbal intelligibility. Instruments: Sociodemographic questionnaire; Voice Handicap Index; University of Washington Quality of Life Questionnaire; Semi-structured script for analysis in the Iramuteq® software. **Result:** mutilation predominated in the palate region. Vocal assessment showed the male sex with worse quality of life, significantly on the Social scale, while the female, Physical scale. Lexical analysis showed needs, frustrations and expectations. **Conclusion:** the study revealed shame, fear, social isolation and, at the same time, the hope of returning to at least being able to speak and be understood by other people through the use of the prosthesis.

**DESCRIPTORS:** Oral neoplasms; Mouth cancer; Oral rehabilitation; Speech intelligibility; Nursing.

### RESUMO

**Objetivo:** investigar o impacto da deformidade bucal oncológica na comunicação oral e na qualidade de vida de adultos e idosos.

**Métodos:** estudo observacional descritivo, transversal, com abordagem mista. Amostra de 41 pacientes submetidos à cirurgia para

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retirada do câncer bucal, resultando em mutilação e inteligibilidade verbal. Instrumentos: Questionário sociodemográfico; Índice de Desvantagem Vocal; Questionário Qualidade de Vida da Universidade de Washington; Roteiro Semiestruturado para análise no software Iramuteq®. **Resultado:** a mutilação predominou em região de palato. Avaliação vocal mostrou o sexo masculino com pior qualidade de vida, expressivamente escala Social, enquanto, o feminino, escala Física. A análise lexical mostrou necessidades, frustrações e expectativas. **Conclusão:** o estudo revelou a vergonha, o medo, o isolamento social e, ao mesmo tempo, a esperança de voltar a, pelo menos, poder falar e ser compreendido pelas outras pessoas através do uso da prótese.

**DESCRITORES:** Neoplasias bucais; Câncer de boca; Reabilitação bucal; Inteligibilidade da fala; Enfermagem.

## RESUMEN

**Objetivo:** investigar el impacto de la deformidad del cáncer oral en la comunicación oral y la calidad de vida de adultos y ancianos. **Métodos:** estudio observacional descriptivo, transversal con enfoque mixto. Muestra de 41 pacientes sometidos a cirugía para extirpar el cáncer oral, lo que resulta en mutilación e inteligibilidad verbal. Instrumentos: cuestionario sociodemográfico; Índice de discapacidad de voz; Cuestionario de calidad de vida de la Universidad de Washington; Guión semiestructurado para análisis en el software Iramuteq®. **Resultado:** la mutilación predominó en la región del paladar. La evaluación vocal mostró el sexo masculino con peor calidad de vida, significativamente en la escala social, mientras que la hembra, la escala física. El análisis léxico mostró necesidades, frustraciones y expectativas. **Conclusión:** el estudio reveló vergüenza, miedo, aislamiento social y, al mismo tiempo, la esperanza de volver al menos a poder hablar y ser entendido por otras personas mediante el uso de la prótesis.

**DESCRITORES:** Neoplasias orales; Câncer de boca; Rehabilitación oral; Inteligibilidad del habla; Enfermería

## INTRODUCTION

In Brazil, cancer with primary location in the oral cavity ranks 5th in the incidence list among men and 12th in women, and is undoubtedly a public health problem<sup>1-2</sup>

Most patients have a diagnosis established in the advanced or metastatic phase of the disease, which, added to the aggressiveness of the tumor itself, makes treatment difficult and significantly worsens the prognosis.<sup>2</sup> In recent years, a concern with the quality of life and well-being during and after the treatment of these individuals has been established, factors that will depend on efficient multidisciplinary monitoring throughout the rehabilitation process.

The treatment, for these patients, usually involves surgery to remove an oral malignant tumor, which can lead to the deformity with serious damage in functions: chewing, swallowing and phonetics, as well as in interpersonal relationships, both social and family.<sup>3-4</sup>

Corroborating this context, some authors point out oral communication between human beings as being necessary to establish contact with the other and with the world through the exteriorization of feelings and thoughts.<sup>5</sup> Thus, when the oral communication process is compromised and speech intelligibility is reduced, people with oral and maxillofacial deformities suffer psychological changes that can contribute to social isolation.

Therefore, rehabilitation through intra- and extraoral prostheses in these patients can provide an improvement in quality of life, from the reversal of the isolation condition and the difficulty of oral communication. However, the symbiotic relationship<sup>6</sup> between man and machine (the prostheses) will depend on the success in the rehabilitation process

The physical and psychological rehabilitation of these patients, their family, social and occupational adjustment depend on the work of a multiprofessional team. The nurse, together with the other members of this team, develops activities that allow the exchange of knowledge, systematizing information and actions that complement each other, aiming at the reintegration of these patients into society, thus enabling a better quality of life.

In this sense, the study aimed to investigate the impact of oral cancer deformity on oral communication and quality of life of adults and the elderly.

## METHOD

This is a cross-sectional observational study of the descriptive type, with a mixed approach, developed in reference hospitals in a Oral and Maxillofacial Rehabilitation service, in two capitals in the Northeast of Brazil.

The study population was individuals diagnosed with oral cavity cancer who underwent a surgical procedure to remove the tumor and, as a result, the oral deformity and difficulty in speech intelligibility. Period for data collection - 06/01/2017 to 11/30/2017 - the sample consisted of 41 patients, aged 18 years or older, in conditions to answer the data collection instruments.

Four patients who were unable to respond to the data collection instruments were excluded from the study, and two because they were laryngectomized.

The research data were collected 30 days after the surgery to remove the tumor, from the application of the instruments: Sociodemographic questionnaire; Vocal Disadvantage Index (VDI) protocol which meets the precepts of vocal quality, in terms of monitoring the impact that dysphonia causes in the emotional and physical spheres, as well as in the daily activities of the individual. The greater a result in this protocol, the greater the vocal disadvantage.

For quality of life assessment, the instrument developed for head and neck cancer patients University of Washington Quality of Life Questionnaire (UW-QOL v4) was applied.

These instruments have been validated for use in research in the Brazilian context.

The Semi-structured Screenplay with open questions was also applied - it speaks in text format for lexical analysis through the software Iramuteq® that uses the applicability of Zipf's Law.<sup>7</sup> This Law works with the frequency of appearance of a word in a text, regardless of what this symbology represents alone or together.<sup>8</sup>

The research project was submitted to and approved by the Research Ethics Committee of the Proposing Institution, under Certificate of Presentation for Ethical Appreciation (CAAE) number 53990416.8.0000.5183 and by the Coparticipating Institution, under CAAE number 53990416.8.3001.5205.

## RESULTS AND DISCUSSION

The sociodemographic aspect presented a sample (n=41) consisting, in its majority, of male gender, 23 (56%) people, 15 people (36.6%) with age range between 51 and 60 years, and 26 (63.4%) who declared themselves brown.

The predominant level of schooling, primary schooling, signalled a low level of education, with 19 people (46.3%). It was also observed that the majority 29 (70.8%) reported family income between one and two minimum wages.

The deleterious habits characterized 34 people (82.9%) who claimed to be smokers or had smoked, and 27 people (65.9%) had been alcoholics.

The histopathological diagnosis found a greater predominance of Squamous Cell Carcinoma in 38 participants (92.7%). The palate was the most affected location, with 30 participants (73.1%). It was also found that more than eighty percent of the sample received treatment that included surgery, radiotherapy and/or chemotherapy.

The VDI Protocol, presented in Table 1, does not register significant differences ( $p > 0.05$ ) between the sexes, measured in the domains: emotional, functional and organic.

**Table 1** - Distribution of means and standard deviation of the IDV Protocol responses, in the emotional, functional and organic domains, by gender of participants. Recife, PE, Brazil, 2017

VDI	Male Average $\pm$ SD Median (P25; P75)	Female Average $\pm$ SD Median (P25; P75)	p* value
Emotional	17,89 $\pm$ 9,92	17,52 $\pm$ 9,83	p = 0,906
	20,00 (12,75; 25,25)	18,00 (8,00; 25,00)	
Functional	20,83 $\pm$ 10,07	24,35 $\pm$ 9,24	p = 0,252
	22,00 (14,00; 27,00)	24,00 (17,00; 32,00)	
Organic	12,61 $\pm$ 7,95	13,22 $\pm$ 8,99	p = 0,823
	15,00 (6,00; 17,00)	15,00 (4,00; 19,00)	
Total	51,33 $\pm$ 25,02	55,09 $\pm$ 24,21	p = 0,630
	56,50 (35,50; 71,25)	54,00 (30,00; 75,00)	

Source: Survey data (2017)

\*Through the t-Student test with equal variances.

Table 2 presents a sample in the simple frequency and percentage related to quality of life using the UW-QOL v4 instrument. The responses, compared to the month prior to the diagnosis of Cancer, 14 (34%) stated to be much worse, while four (10%) believed to be much better. In the health variable, in the last seven days, 25 (61%) believed to be bad or average. When considering general health, including physical and mental health, family, friends, and spirituality, 27 (66%) rated it average or bad.

**Table 2** - Distribution of the sample in simple frequency and percentage related to quality of life, through the instrument UW-QOL v4 (Washington). Recife, PE, Brazil, 2017.

Variable	N	%
<b>TOTAL</b>	<b>41</b>	<b>100,0</b>
<b>How do you rate your quality of life compared to the month before you develop cancer</b>		
Much better	4	10
A little better	5	12
More or less	9	22
A little worse	9	22
Much worse	14	34

Variable	N	%
<b>How do you rate your health-related quality of life in the past 7 days</b>		
Excellent	3	7,3
Very good	4	9,8
Good	7	17,1
Average	13	31,7
Bad	12	29,3
Very bad	2	4,9
<b>How do you rate your quality of life in general</b>		
Excellent	1	2,4
Very good	3	7,3
Good	8	19,5
Average	18	43,9
Bad	9	22,0
Very bad	2	4,9

Source: Survey data (2017)

The answers to the questions in the Semi-structured Script were put in text set format (corpus) and represented in tag cloud (word cloud) in Figures 1 and 2.





In Brazil, there is a cultural mark, which leads to the absence, in a general way, of the male population in the health service for the prevention of diseases, as shown by the predominance of the male sex in this research corroborating estimates presented by other studies.<sup>1-2</sup>

The significant presence of brown color in research subjects disagrees with other studies, in which the predominance of white color is highlighted.<sup>9</sup> Perhaps because it is a research developed in a region of the country, where, according to the National Household Sample Survey<sup>10</sup>, it reveals that, on the criterion of color or race, most of the population living in northeastern Brazil is made up of black and brown individuals, substantiating the findings in this study

It is noted that most of the sample appears between 51 and 70 years, according to previous surveys<sup>11-12,2</sup>, which highlight an increase in the number of cases diagnosed with oral cancer in this age group, especially in the male population.

The association between the diagnosis of oral cancer and the low level of education found in this study, mostly between primary school and illiterate, can be justified by other authors<sup>11</sup> in which they point out that the low level of education can hinder the awareness of health care needs throughout life. The predominance of low family income is also associated, in which the disease appears in clinical and epidemiological studies, with more prevalence in a population with low economic resources. Therefore, it is essential to emphasize that the low level of schooling and the scarce family income can be considered factors that negatively propitiate the increased risk of oral cancer.

It is also important to point out that most of them have been abusing alcohol and cigarettes for several years, which reiterates the proven association of these habits with oral cancer.<sup>13-15</sup> These drugs, associated or not, interfere negatively in the quality of life of these individuals.

The study identified Squamous Cell Carcinoma (SCC) (92.7% of the sample) present in the histopathological diagnosis. The location of the tumor, on the palate, is in 73% of the cases, which corroborates studies by Vergo and Andrews, cited by Goiato<sup>16</sup>, when they state that this region is quite affected, being responsible for the fourth placement in all types of head and neck cancer.

Surgery associated with radiotherapy (RT) was the therapeutic modality indicated in 49% of the individuals, and the association with chemotherapy (QT) was found in 37% of the sample. These data are in agreement with research by Dedivitis et al., quoted by Goiato<sup>16</sup>, when they found that patients diagnosed with oral OHC, 47% had undergone surgery and RT.

After surgery to remove the tumor, these individuals found that they had permanent sequelae (oral and nasal communication), resulting in poorly understandable speech.

In the evaluation of the IDV instrument, for the Organic scale, the questions that presented the highest score were: "People ask: 'What do you have in your voice?'" and "I make a lot of effort to speak. In the Functional domain, the highest score was for the questions "People have difficulty hearing me because of my voice" and "People have difficulty understanding me in noisy places". On the Emotional scale, the highest score

was for the issues "My voice problem pisses me off", "I became less expansive because of my voice problem" and "My voice makes me feel disadvantaged". This result was similar for both genders, corroborating other studies<sup>17</sup>, which used the same protocol to evaluate dysphonic patients.

The analysis of the UW-QOL v4 instrument identified similarities and differences between the sexes, making it possible to observe that males had worse Global Quality of Life (GQL). However, for both sexes, QLQ was more expressive in 'much worse' at the time of the interview, compared to the month before the diagnosis of cancer. However, when asked how they rated the quality of life in general, during the last seven days, 63% considered between 'good' and 'average', a fact explained when they reported the suffering present from the discovery of the diagnosis, also going through the phases of different treatment modalities that included surgery, RT, QT and/or association of these.

For the male gender, the expressive difference occurred in the Social scale, while for the female, the Physical scale became more evident. This finding corroborates the theory of emotions<sup>18</sup> that identified the social body of men and women.

In this theory<sup>18</sup>, the woman defines herself by the quality of her appearance. A woman will always be defined as good or not through her physical presentation. Even if she has a good social position, career success, among other qualities, if her body is very out of the standards or presents mutilation, she will not be a woman to get involved sexually. There is an important inequality between men and women from this point of view. While, for men, for example, it is not their beauty that matters most, but their social position, their profession.

The lexical analysis, belonging to the discourse manifested by the individuals, highlighted needs, frustrations and expectations when analyzed by Iramuteq® software. Tag clouds, word classes and similarity analysis made it possible to clearly identify the similarity with the responses to the instruments used for quantitative analysis, when it revealed shame, fear, social isolation and, at the same time, the hope of being able to eat, to speak and be understood by other people again. These functions are at the base of Maslow's pyramid<sup>19</sup> concerning the chain of human needs, whose base is the lowest needs (physiological or basic needs) and, at the top, the highest needs (the needs of self-realisation).

The process of caring, which concerns the scope of oral and maxillofacial rehabilitation, involves attitudinal, psychosocial, economic and political components, in which the nurse needs to recognize that this magnitude is essentially dynamic, multi and interdisciplinary. Therefore, a diverse repertoire of knowledge and capacity is relevant, making him/her capable of making, executing and evaluating the best decisions, even in unpredictable circumstances.

## CONCLUSION

The study pointed out that oral deformity of oncologic origin impacts directly on oral communication. It revealed shame, fear, social isolation and, at the same time, the hope of at least being able to talk and be understood by other people through the use of the prosthesis. It also showed that

Zipf's theory, through the software Iramuteq®, enabled a more modern lexical analysis for nursing.

The nurse has a structuring and fundamental role in the whole process involving oral and maxillofacial rehabilitation, since the patient relies on him in search of emotional support and guidance to satisfy his basic needs. By understanding the magnitude of this rehabilitation process, the nurse positions himself as an awakened agent, to implement properly planned actions that not only aim at the prevention of other sequelae, physical recovery and improvement of quality of life, but also aim at the autonomy and reintegration of these patients into society.

It is pertinent to reflect on the need for more studies on the subject, in the area of nursing, which carries, in its essence, the science and art of caring, in order to offer efficient, integral and optimized assistance.

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