

# QUALITY OF LIFE IN TOTAL LARYNGECTOMY PATIENTS: AN ANALYSIS OF DIFFERENT ASSESSMENT TOOLS

## *Qualidade de vida em laringectomizados totais: uma análise sobre diferentes instrumentos de avaliação*

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### ABSTRACT

**Purpose:** to verify the different questionnaires and semi-structured interview contribution for quality of life assessment in individuals with total laryngectomy. **Methods:** quantitative and qualitative research with a semi-structured interview and specific questionnaires for head and neck cancer application – UW-QOL, FACT (H&N) and EORTC QLQ (H&N35) – in four patients aged 62-68 years who underwent total removal of the larynx and they are in speech therapy for acquisition of esophageal speech. **Results:** the semi-structured interview allowed better listening. However, population studies invalidate the interview application and the questionnaires become the better choice. The EORTC QLQ (H&N) proved be the most specific questionnaire for speech therapist questions, while the UW-QOL explores further physic questions and the FACT (H&N) covers the emotional/psychological domain. **Conclusion:** the questionnaires and the semi-structured interview presented many specifications and their contribution for quality of life assessment are different. The more appropriate choice depends on the goals of research and the primordial factor for a quality of life assessment.

**KEYWORDS:** Speech, Language and Hearing Sciences; Quality of Life; Laryngectomy; Questionnaires

### ■ INTRODUCTION

Head and neck cancer (HNC) represents 2% of all occurrences of neoplasms in Brazil. Larynx cancer, in turn, is responsible for 25% of these cases<sup>1-3</sup> manifesting itself most often in male persons aged 55 years and over<sup>1,2,4,5</sup>. Its first symptoms are dysphonia – represented by hoarseness –, dysphagia, dyspnea and odynophagia in varying degrees, depending on the tumor location, size and infiltration<sup>6,7</sup>.

Although the early diagnosis of a multidisciplinary team is ideal, given the increase of more conservative healing and therapeutic possibilities<sup>7,8</sup>, approximately half of patients when diagnosed are already with tumors in advanced stages<sup>9</sup>. For these cases, total laryngectomy (TL) is the most common surgical procedure<sup>10,11</sup>, associated with radiotherapy (RxT) and/or chemotherapy (ChxT) sessions<sup>12</sup>,

accompanied or not by ganglion resection – cervical drain – with the creation of a tracheostomy and closing of the pharyngeal wall<sup>13</sup>. The laryngeal functions, therefore, such as breathing/olfaction, phonation and sphincter, can be compromised<sup>14-16</sup>, as well as the emotional and psychological aspects<sup>17</sup> linked to these changes and related mainly to appearance.

The assessment of the quality of life (QOL) of patients with laryngeal cancer, whose indicated treatment is the TL, represents a useful tool for providing a better understanding about the main difficulties of these patients and their priorities before and after the surgical treatment, favoring a multidisciplinary assistance that is efficient, integral and optimized to health<sup>2,18</sup> and a choice of the most effective and friendly treatment for each case<sup>12</sup>.

According to the World Health Organization (WHO) – Quality of Life Group: WHOQOL, 1993 – the QOL is a multidimensional, dynamic and subjective concept involving not only the health status or the success of a treatment, but also the biopsychosocial well-being of the patient<sup>19</sup>. Therefore, the importance of considering the longitudinal follow-up of

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the QOL and paying attention to the resulting time between surgery and the date of the assessment is highlighted, since the immediate impact to the treatment tends to be greater than in the subsequent months<sup>20-23</sup>. Over the years, the QOL has become an indicator of the effectiveness of different treatments, the physical and psychosocial impact of diseases and the production of knowledge of professionals and researchers<sup>24</sup>.

Although the questionnaires have proved to be good assessment tools, it is believed that some important aspects involved in the QOL end up not being contemplated in their application, among which we want to mention the individual religious, cultural and historical factors of the subject.

Therefore, this research is justified by the need to observe and to deepen the understanding of the specific demands of the population with larynx cancer and to contribute to the improvement of the provision of cancer care within the field of Speech Therapy. From this, we intend to verify the contribution of different questionnaires and a semi-structured interview in the assessment of the quality of life in individuals with total laryngectomy.

## ■ METHODS

This is a quantitative and qualitative study approved by the Research Ethics Committee of UNICAMP with opinion No. 114.978 and had the participation of the subjects upon the signing of the Informed Consent.

As an inclusion criterion, we considered adult subjects undergoing full removal of the larynx associated with additional treatment by radiotherapy or chemotherapy, of both genders, who were in speech therapy follow-up for the development of esophageal voice. We eliminated subjects that used tracheoesophageal prostheses and patients without availability to participate in the research. Initially, we surveyed the chart of total laryngectomy patients accompanied in the CEPRE (Centro de Estudos e Pesquisa em Reabilitação Prof. Dr. Gabriel Porto/ UNICAMP) and, after checking, the subjects were contacted and submitted to the application of four instruments of assessment of QOL in HNC randomly applied in order to avoid any influence of the sequence of application in the responses. Thus, the order of application of the four instruments was

different for each of the four participants in the research who fulfilled the criteria of the study. The data were collected in a month.

The selected instruments consisted of three self-applicable questionnaires validated for Brazilian Portuguese<sup>25,26</sup>: University of Washington – Quality of Life Questionnaire (UW-QOL); Functional Assessment of Cancer Therapy (FACT-H&N); European Organization for Research and Treatment of Cancer (EORTC-C30/H&N 35), considered by the International Conference on Quality of Life held in Virginia, USA, in October 2002, as the most used questionnaires for the evaluation of QOL in patients with HNC, and a semi-structured interview. The interview was created based on the domains included in all questionnaires and structured in five general topics: characterization and contextualization of the case, physical well-being, psychological and emotional well-being, social relations, and communication and swallowing (Figure 1). However, we added to those domains aspects that are not covered in the questionnaires, such as the religious one. We began the interview with a broad question able to arouse the interest of the participant to expose some points that they believe to be important to mention: “Tell me a little about your history; what was your life like before diagnosis and how your trajectory was.” When some of the topics listed in the script were not mentioned, we made a more direct question so that the patient could speak in more detail on the subject. The questions followed the model: “How would you rate”, “what do you think about”, “what is your opinion”. We chose to not perform the video filming/ recording of the interview, as we could not capture the audio, since the intelligibility of the speech could be compromised or hindered because of the means of communication of each of the patients of the research. The transcription was performed at the time of the interview.

The analysis of the results was obtained by crossing the information extracted in the interview with the answers given in the questionnaires, using in particular the scores calculated in accordance with the recommendation of each instrument<sup>25,26</sup>. In Table 1, we bring reflections on each of the assessment tools, including their ways of structuring and implementation, respecting the proposed domains for each one in the analysis.

**I) Characterization of the subject and contextualization of the case**

- 1) General information about the subject (age, former profession, economic situation, origin)
- 2) Account of the trajectory and the clinical care (date and place of the diagnosis, treatments performed – including laryngectomy–, time between diagnosis and surgery, search for alternative treatments)
- 3) Information about family aspects (members of the family, relationship with the family before and after receiving the diagnosis, role of the family in the life of the subject)
- 4) View that the subject has over what is/was the cancer in their life
- 5) Psychiatric morbidities that emerged with the diagnosis: depression, isolation, anxiety, religion.
- 6) Acceptance and psychological reactions that came up with the diagnosis: denial, regression, guilt/punishment, anger, shame.
- 7) Opinion on what has changed in the life of the subject and what are the biggest recent problems arising from larynx cancer.
- 8) Opinion on their quality of life before and after diagnosis and treatment

**II) Social Relations**

- 1) Performance of physical exercises
- 2) Recreation activities
- 3) Persons with whom they have contact
- 4) Difficulty in socializing with friends and family
- 5) Search for and participation in religious institutions

**III) Physical well-being**

- 1) Manifestations of pain (facial region, neck, shoulder, other parts of the body)
- 2) Feeling of weakness
- 3) Opinion about/Uncomfortable with current appearance
- 4) Ability to work and/or perform tasks independently
- 5) Feeling of willingness
- 6) Weight loss or gain
- 7) Use of medicine

**IV) Psychological and emotional well-being**

- 1) Mood
- 2) Anxiety/concern
- 3) Sadness
- 4) Satisfaction on how to deal with the disease

**V) Speech-language aspects**

- 1) Aspects of chewing (difficulties after surgery, characteristics of the food consumed - volume, consistency, temperature -, oropharyngeal motility, difficulty of food bolus propulsion, degradation or loss of dental elements, change in the perception of taste and reduced production of saliva)
- 2) Aspects of swallowing (odynophagia, difficulty in swallowing different consistencies of food - liquid, nectar, honey, flan, solid -, presence of gagging and coughing, multiple swallows or forced swallowing, conduction of maneuvers to facilitate swallowing, pneumonia)
- 3) Phonoarticulatory aspects (method of voice production, greater difficulties with communication, understanding of the interlocutors)
- 4) Breathing problems

**Figure 1 – Interview guide**

**Table 1 – Presentation of the scores of each of the patients studied among the domains addressed in the three quality of life questionnaires**

	QUESTIONNAIRES	SUBJECTS			
	Domains	GA	NO	OR	JO
<b>UW-QOL</b> (total –1200)	Pain (0-100)	100	100	100	100
	Appearance (0-100)	50	100	100	75
	Activity (0-100)	100	100	75	100
	Recreation (0-100)	100	100	100	100
	Swallowing (0-100)	67	100	100	67
	Chewing (0-100)	100	50	100	50
	Speech (0-100)	67	33	67	67
	Shoulder (0-100)	100	33	100	100
	Taste (0-100)	100	67	100	33
	Saliva (0-100)	100	33	67	67
	Mood (0-100)	75	75	75	75
	Anxiety (0-100)	100	67	100	100
	Total	959	858	1084	934
	<b>FACT-H&amp;N</b> (total –144)	Physical well-being (0-28)	17	18	27
Social/family well-being (0-28)		7	14	11	5
Emotional well-being (0-24)		14	18	23	21
Functional well-being (0-28)		17	16	7	22
Additional concerns (0 – 36)		12.75	17.25	12.75	13.5
Total		68.75	82.55	84.75	103.6
<b>EORTC QLQ – H&amp;N35</b> (total – 135)	Physical (0 – 56)	21	25	17	22
	Emotional (0-16)	15	7	4	5
	Social (0-32)	19	25	17	13
	Pain (0-16)	4	5	4	4
	Dyspnea (0-8)	4	3	2	1
	Weight loss (0-8)	2	2	2	2
	General condition (0-4)	1	2	1	1
Total	66	69	47	51	

Caption: Calculations performed based on the instructions for each questionnaire, present in VARTANIAN, 2007. The abbreviations GA, NO, OR, and JO are the abbreviations of the names of the subjects of the research, and they were chosen to maintain confidentiality

## ■ RESULTS

Four total laryngectomy patients that contemplated the inclusion criteria of the study agreed to participate. All are male, have similar social conditions and showed smoking and drinking habits for nearly all their lives, being two of them (50%) functional illiterates. They received the diagnosis of squamous cell carcinoma (SCC) in the larynx when they were approximately 59-66 years of age at an already advanced stage (staging III and IV) with a range of no more than a year between diagnosis and surgical intervention at the Clinics Hospital of

the University of Campinas (HC/Unicamp), with cervical drain, each with their specific characteristics. After the procedure, they complemented the treatment with 35-40 sessions of radiotherapy, and two of the subjects (50%) were also subjected to 3 and 6 sessions of chemotherapy (Table 2). We note that, in addition to the SCC of the larynx, two of the subjects presented recurrence in other organs, being subjected to more than one surgery to remove the tumors.

Table 1 shows the overall results obtained in each questionnaire, which will serve as a basis for a cross-check of the information contained in the interview.

**Table 2 – Characterization of the patients according to age, gender, tumor staging, year of diagnosis and surgery and start of the speech therapy treatment**

Id.	Age	Gender	Staging	Year of diagnosis	Year of laryngectomy	RxT	ChxT	Start of the speech therapy
GA	68	Male	T <sub>4</sub> N <sub>2</sub> M <sub>x</sub>	2003	2004	36	-	2011
JO	62	Male	T <sub>3</sub> N <sub>2</sub> M <sub>0</sub>	2009	2010	35	-	2011
NO	68	Male	T <sub>4</sub> N <sub>2b</sub> M <sub>0</sub>	2010	2010	35	3	2011
OR	72	Male	T <sub>4</sub> N <sub>2</sub> M <sub>0</sub>	2007	2007	40	6	2010

Caption: RxT – amount of radiotherapy sessions; Chxt – amount of chemotherapy sessions; Staging – TNM classification of malignant tumors: T (tumor size), N (presence of tumor cells in the lymph nodes) and M (presence of distant metastasis). The abbreviations GA, NO, OR, and JO are the abbreviations of the names of the subjects of the research, and they were chosen to maintain confidentiality

## ■ DISCUSSION

We can see in Table 2 the time elapsed between the diagnosis of cancer and the beginning of the speech therapy sessions. It is known that access to certain health services in Brazil is still very deficient and demands more time than recommended. We can notice that the period between the diagnosis and the start of the speech therapy intervention ranged up to eight years. The long wait time to receive this type of care goes against what is advocated for the proper recovery in patients with HNC, since a speech therapist should be part of the team still in the pre-surgical evaluation<sup>26,27</sup>. We can justify this fact by the scarcity of professionals hired to work in oncology, difficulties in the access to services, lack of information and difficulty in making progress in the decisions made.

Next, we will present some aspects raised with the interview, whose application had an average length of 20 minutes, and that will be crossed with the results presented in Table 1 and Table 2.

In a first moment, the participants brought information about their origin, work, family formation,

changes brought by the disease diagnosis and feelings that emerged from the events. Then, they detailed some aspects that the patient himself or the interviewer considered to be more significant, such as spirituality, coping and family, for example, considering the particularities of each case. The interviews were organized according to the general topics of the script of the interview and compared with the results of the questionnaires.

### I) Characterization of the subject and contextualization of the case

In this first topic, it is worth mentioning the subjects' opinion about their QOL before and after the recommended treatment; a dynamics that is hardly possible to be checked only with the application of questionnaires. Although the vast majority of the patients consider the QOL worse after the diagnosis, which is usually expected<sup>18,28-30</sup>, there are those who break the paradigm and see life differently. Through diagnosis, they find a way of valuing life and rethink its meaning. A fairly significant example that highlights the subjectivity of the QOL is the case of the subject GA, who emphasizes how the



family was the most influential factor in their opinion on QOL. GA was the only one of the respondents to consider improvement after the disease, and he assigns this assessment to the social/family aspect, showing that the lack of family support caused the most discomfort turning the inconvenience into a way to rethink his values.

*"For me, I think I'm better now, because with what happened I got to know who really is my family. I got to know my friends ". [GA: 05/Oct/2012]*

Of the three questionnaires considered, the only one who directly addresses the opinion related to QOL is the UW-QOL. It has twelve closed and quite specific questions and, despite that, it also has three open questions where we can observe the concern to investigate QOL before and after diagnosis/treatment. This way, the questionnaire greatly increases the dynamic analysis of the QOL over time<sup>21</sup>. The EORTC QLQ (H&N) does not address the QOL at all. The FACT (H&N) brings a question for the subject to quantify using the Likert scale their general health condition.

## II) Social Relations

The social institutions in which the subjects are involved represent a key role in the fight against the disease, for in them lies the necessary support to overcome it. Among these institutions, we can mention the most representative ones in this study: family, friends, and Church.

It is important, at this point, to reflect on the importance of family because society supposes that it will be this institution that will assume the care of the subject and support them at every stage of their treatment. We can observe that families are little prepared to face the situation along with the patient. The subjects who received constant family support and got closer to their family after the diagnosis did not complain for a moment about their social/family domain, while the subjects who felt deprived in this respect were strongly resented, as we already observed in the previous topic. Next, we expose a few more examples:

*"I came to my brother's home, but it didn't work. It was for a short time. My sister-in-law started to be disgusted by me, [...] Then I walk out and I've been living alone until today. [...] For me, family is over." [GA: 05/Oct/2012]*

*"The woman was disgusted by me [...] The grandson took care of me... When I got well*

*again, she wanted to come back, but I didn't want anymore." [OR: 11/Nov/2012]*

The only questionnaires that address the family matter is the FACT (H&N) and the EORTC QLQ (H&N 35), while the UW-QOL does not mention this aspect, being restricted to the functional and physical ones.

During the application of the questionnaires, the explanations that the participants offered on their own answers were important in understanding the real situation in which they found themselves. Subject GA, for example, both in the interview and in the questionnaires, brought explanations about the family matter, as this is the reason that bothers him since the onset of the disease. When asked in the EORTC QLQ (H&N 35) about having found family problems over the past seven days, he responded negatively getting a good score on the issue. However, he says that the answer is positive because he is away from his family, which does not care about him anymore. Thus, we see that the score achieved in this item does not reveal his reality and how his family matter is much more complex and could be better addressed with the interview.

One aspect not covered in any of the questionnaires and that was constantly mentioned was the religious one. It is believed that religion can significantly influence the QOL, as it can reconnect the patients with God and even the family, making them reflect about life before the illness. It is known that diagnostics can make individuals seek solace in religion and that, often, they assign their overcoming to it<sup>31</sup>. Thus, some persons even consider improvements in QOL even after the diagnosis and treatment of cancer. Two statements of the interview can exemplify it:

*"If I weren't a Christian, I wouldn't be alive anymore. What happened brought me closer to God and makes me alive. My life is a miracle." [OR: 05/Oct/2012]*

*"I've always been Catholic. I asked a lot from God, to help in the situation. This helped me cope. Then, I became peaceful. Now I'm fine." [JO: 24/Nov/2012]*

## III) Physical well-being

According to the reports, we can note how the physical aspects also have great impact on the QOL, because of the change in appearance and the limitations that the disease or the caregivers often impose them, in order to protect them. Some even overcome the discomfort of a tracheotomy or a cervical drain, for example, while others still

resent it because they have to live with this type of change. What is evident is that, during the period of treatment with RxT and/or ChxT, these patients are more debilitated both emotionally and physically and demonstrate a greater embarrassment with their own image:

*“At the time I didn’t want to live. With the neck cut like that, awful” [OR: 11/Nov/2012]*

*“I don’t feel any pain, but I have a weakness in the shoulders It bothers me, here I points to the cervical region and shoulders / It is ugly” [NO: 19/Nov/2012]*

At the time of treatment, all of them had to stop their work and everyday activities, mainly because of the discomfort that they felt, and currently they try to be active, even by doing domestic activities. Although years after treatment, they returned to perform some activities. All of them regretted having to change the habits of an active life.

In addition to feeling weakened and mutilated, they also lost a lot of weight throughout the treatment. This nuisance, however, was only possible to be realized with the interview, although this aspect is also addressed in the questionnaires. The fact is that these instruments refer always to the last seven days and, often, the subject did not suffer changes during this period, but over weeks, months or years. A clear example is the issues related to pain and weight loss/gain<sup>32,33</sup>; all participants lost weight with the treatment, but the answer in the questionnaire could not contemplate such a variable, as no alteration was observed in the last week. Therefore, the result obtained in the questionnaires comes from the time period and does not give us a view about the dynamicity of the QOL. This fact was pointed out by two of the participants during the interview:

*“now I have no problem, but before I had a lot” [GA: 05/Oct/2012]*

*“this week nothing changed, but I lost a lot of weight. It bothered me a lot at first, now I’ve accepted it, what can I do?” [OR: 11/Nov/2012]*

#### IV) Psychological and emotional well-being

We can observe in the speech of each participant that the way how they faced/face the disease changed according to the period of treatment and the support they received. The life story of each one, their experiences and personality, for example, positively or negatively affect how they confront a symptom, that is why some individuals face a

given situation better than others<sup>34</sup>. As soon as they discovered the cancer, they were dominated by feelings such as fear, worry, anxiety and especially guilt: feelings that show that the concept of cancer still remains associated with suffering and death<sup>34</sup>. However, over the years, they have learned to overcome and live, in their own way, with the consequences of the treatment or the limitations arising from it. It is evident in the course of the disease the phases by which the patients pass through: initially they reveal a great shock upon receiving the diagnosis, accompanied by feelings such as guilt, depression and anger, which are soon replaced by denial and, subsequently, by acceptance and adaptation in view of what was left to them<sup>35</sup>.

All this individual process directly affects the assessment that they have about their QOL. There are revealing reports that point to this dynamic of feelings ranging from a yearning for death up to a humorous way of wanting to prolong life.

*“I felt dead already. I asked to die. What happened was even good. Soon after the surgery I was feeling awful, now I am well again. But I felt very guilty because I smoked.” [OR: 11/Nov/2012]*

*“At first I was angry. At the time I was very concerned [...] about dying. Today, my life is normal. It isn’t like it was before cancer. There’s no way, some things always change, but we have to adapt. But now I’m happy. It was a good thing because I learned other things: cooking, baby-sitting my grandson ... I stay home, rest, take care of the garden.” [NO: 24/Nov/2012]*

In the interview, we could discuss in more detail about the moment in which feelings, such as guilt and fear, emerged. However, with the questionnaires, mainly with the application of FACT (H&N), which discusses the emotional issues, these domains were little or not affected. This does not mean that they have not existed, but that they are no longer involved in the assessment of the QOL of the subjects. Because of the stage of life they are in today, much of the emotional weakness that they suffered was overcome by a long period of adaptation.

In studies conducted with the UW-QOL<sup>22</sup>, anxiety was a very impactful factor for the population researched. However, the participants’ answers in this research had almost no impact on the application of the same questionnaire, and anxiety did not appear as an emotional complaint in the interviews, as we can see in Table 1.

In the results of the EORTC QLQ (H&N), the domains that seemed to be significant were the social and emotional functioning, which is consistent with the literature on it<sup>9</sup>. It is important to mention that appearance and sexual satisfaction are covered in the emotional domain and not in the physical one, and they did not appear to be affected in the population investigated.

## V) Communication and Swallowing

Through the assessment of the QOL, we can note that phonation and chewing are aspects fairly impacted in the life of the subjects. With the interview, we could understand the anguish of the patients about their phonoaudiological complaints and measure how much they value the therapeutic intervention, even if late. All participants revealed, at some point of their life, important compromises in communicating and eating.

We can observe that when there is a complaint about swallowing there are also complaints about phonation, and the opposite is also true, which can be justified because such functions happen at the same anatomical structures. As for swallowing, there are reports of difficulties in conducting the ejection of the food bolus, chewing – because of the loss of dental elements and bad adaptation of the dentures – and the presence of nasal reflux<sup>10-12</sup>. Regarding speech, we can observe the anguish of those who are unable to do be understood by others (OJ, GA and NO) and the satisfaction when the loss of voice is overcome and the possibility of communicating well again (OR).

*“There are people who become nervous because they don’t understand me. Some don’t even want to talk. The therapy is helping a lot. Now it’s easier.” [GA: 05/Oct/2012]*

*“The biggest problem was the voice, to speak, to talk. What bothers me the most is not being able to speak. I want to talk about things, people don’t understand, then they are in a bad mood. I became sad, I don’t have that joy anymore. [...] I see things, I want to speak, but I can’t. It feel bad and I start crying.” [NO: 19/Nov/2012]*

*“I didn’t speak anything, until the therapist though me again how to talk. It’s not normal, but I can be understood. It gives me joy. [...] When I woke up, got up and couldn’t speak, I asked the doctor to kill me.” [OR: 11/Nov/2012]*

It is evident how much the loss of voice qualitatively interferes in the communication and in the social relations of these subjects and how this deprivation influences the emotional and social issues. Speech is the main instrument of communication and voice represents the identity of a subject. Its removal compromises expressions of feelings and desires. Therefore, the loss of voice after TL has been shown to be the most striking factor in the subjects assessed<sup>2,23</sup>. Therefore, the rehabilitation of these patients is one of the most valuable contributions that Speech Therapy can offer, which involves much broader aspects than voice production.

Based on the multidimensional and subjective concept of QOL, the interview has been shown to be a fundamental instrument that provides an approximation with the subject enabling a better understanding of their needs at different times of their lives. In order to ‘hear’ the subject, we have to watch their gestures and their whole way of saying things, as if we though using their thinking, abstracting from any prejudice or bias. The interview allows this interaction, in addition to better exploring a desired domain, be it more interesting for the evaluator – such as the speech aspects – be it more important to the subject, because it seems to be a more impactful factor<sup>28</sup>.

In accordance with the information obtained in the interview, we can note that in the three questionnaires the speech was the domain that most appeared compromised even after the long time elapsed after diagnosis and treatment. In the EORTC QLQ (H&N 35), speech, because of its communicative function, and the difficulty in eating in front of other people are considered within the social domain and appear significantly affected. In the UW-QOL, the score indicating greater dissatisfaction was also related to speech area, along with the discomfort with xerostomia – dry mouth –, which in other studies also appeared quite affected both in the application of the EORTC QLQ (H&N 35)<sup>22</sup> and the UW-QOL<sup>2</sup>. Finally, in the FACT (H&N), there are questions about speech and swallowing in the domain of additional concerns, which appeared considerably impaired.

We highlight the fact that the participants of the research have been attending a speech therapist for a few years seeking the improvement of communication, which points to the need that they feel to maintain an effective communication. It is important to verify if the speech remains with such an impact on the QOL in other populations.

So that a questionnaire can be validated, it must undergo tests and be applied in a large number of the population with HNC in order to become a safe and reliable method of assessment. Thus, they are



valuable instruments, although they have limitations. Each one carries particular characteristics and contemplates what their creators considered to be most important for the assessment of the QOL, and they can be applied by different health professionals. Overall, QOL assessment questionnaires can be divided into generic and disease-specific. The ideal would be to start with the overall assessment of the patient; however, its application is long and tiring, this way disease-specific questionnaires are chosen. These fulfill the task efficiently and are considered safe and sensitive<sup>25,28,30</sup>, aimed at better understanding the real impact of the HNC.

Although the questionnaires that this research used have been designed to be self-applicable, the researcher had to do their implementation, bearing in mind the difficulties that the subjects had in reading and understanding them – both the two functional illiterates and the two literates – and the preference that they themselves exposed to have someone to assist them. When they still did not understand the question, this was asked again by up to four times. The application of EORTC QLQ (H&N 35) and UW-QOL lasted for approximately 10 minutes and the FACT (H&N) approximately 15 minutes, twice as long as disclosed by their creators, as the subjects constantly did not stop at the questionnaire and felt the need to explain their answers or specify any event related to it, showing a clear need to be heard.

When comparing the three questionnaires, we can realize that some topics were addressed in all of them and considered as critical for the assessment of the QOL such as: pain, taste, saliva, speech and communication, swallowing and chewing, and some appear more specified than others. However, a large number of aspects were only considered in only one of the questionnaires. Namely: shoulder (because of cervical drain) was only addressed in the UW-QOL; sense of smell, weight loss/gain and use of medicines or catheter were only mentioned in the EORTC QLQ (H&N 35); whereas, in FACT (H&N) factors such as sleep, family support, motion sickness and use of alcohol and cigarettes were addressed. In addition, we verified that the FACT (H&N) does not contemplate any question about appearance, but it explores the emotional and social

issues, becoming a reference when the researcher wants to pay attention to psychological issues, while the EORTC QLQ (H&N 35) does not directly question the opinion about the QOL and also does not consider feelings such anxiety, worry and fear, but it is the more specific questionnaire and explores the issues with language, highlighting the swallowing difficulties in relation to solid, paste and liquid foods, for example. The UW-QOL does not explore the social issue, addressing more deeply the general physical aspects and their repercussions.

Despite the three questionnaires being specific to HNC and assessing similar aspects, how these domains are categorized and weighted can cause variations in the results when compared. There were participants who received better scores on a questionnaire and worse in another, showing that there is a difference between the factors they consider important for the assessment of their QOL. Subject GA, for example, received greater scores than subject NO in the UW-QOL questionnaire (GA: 68.75/144; showing a QOL of 47.2% and NO: 85.55/144 revealing a QOL of 61.50%), however, he received lower scores with the FACT (H&N) (GA: 959/1200, 79.9% and NO: 858/1200, 71.5%). We have to consider that the answers of all subjects have remained consistent in the application of the three questionnaires (Table 1).

In virtue of the scores, it is worth noting that in the UW-QOL and FACT (H&N) the higher the score the better QOL, while in the EORTC QLQ (H&N 35) the reverse is true. With it, we can see in the results that the domains that are more impacted in all of them were speech and swallowing, and that there is a relationship between them in relation to the seriousness of the problem, as noted in the interview. In fact, the sequelae take on a much broader dimension in the repercussions than the fact that they have difficulties in speaking and swallowing or the presence of a physical deformity<sup>22</sup>.

In Figure 2, all aspects covered in the questionnaires are schematized as a way to facilitate the comparison between them and assist in choosing the best research tool depending on the purpose of the researcher/therapist.

ASPECTS	FACT (H&N)	UW-QOL	EORTC QLQ (H&N35)
Anxiety	X	X	X
Appearance		X	X
Activity/Work	X	X	X
Fatigue	X		
Swallowing	X	X	X
Dyspnea	X		X
Pain	X	X	X
Nausea	X		
Speech/Communication	X	X	X
Family	X		
Smoking/Drinking	X		
Mood	X	X	X
Chewing	X	X	X
Medicine			X
Smell			X
Shoulder		X	
Taste	X	X	X
Weight			X
Concern	X		
Quality of life	X	X	
Recreation	X	X	X
Sex life	X		X
Saliva	X	X	X
Satisfaction	X		
Feeling of illness	X		
Sleep	X		
Catheter			X
Sadness	X		
Voice			X

**Figure 2 – Aspects addressed in the questionnaires for Head and Neck Cancer**

We observed that the application of the UW-QOL was harder for the patients leaving them confused with the possible answers. They presented questions and sometimes revealed not being satisfied with the alternatives offered, which are very specific and closed. The language is more complex and the alternatives had to be repeated several times until we received a reply. Some authors also consider as a limitation in the UW-QOL the fact that it does not bring issues that cover sexual performance and occupational and financial aspects<sup>22</sup>, which sometimes interfere in the QOL of some subjects.

The EORTC QLQ (H&N) was the questionnaire of easier understanding with simple language and more suitable to the whole population. The alternatives, on the Likert scale, promoted better answer options by quantifying the perception that the subjects had about each factor. Although it was self-applicable as the other ones, it was the only one built upon a direct speech in the form of questions

and using a pronoun that commonly is used as the second-person singular – the “you”. We believe that this format helped to facilitate the understanding of the subjects.

Through the testimony of the participants, it is evident how the concept of QOL is subjective and variable, depending a lot on the whole context of the case. In general, we can see that the answers to the questionnaires agree with the interview, but the last method of assessment better encompassed the whole situation of the patient and allowed a greater understanding of each case. Often, the answers obtained from the questionnaires do not receive interpretations and clarifications that may help in understanding the QOL in all its dimensions, whether for research purposes or for directing the best treatment.

Therefore, we believe that the choice of instrument to be used by the therapist/researcher is a primary factor for a proper assessment of the QOL. Both the

questionnaires and the interview demonstrated that the domains most affected in this population were the speech, emotional and social ones – the latter often resulting from the communication difficulty itself – although they brought different contributions for the assessment of the QOL. We have to consider that the subjects evaluated are undergoing speech therapy, which implies that they searched for the service as they still felt very disturbed with the loss of voice. We believe that a research contemplating the assessment of the QOL of total laryngectomy patients with a larger number of participants in different stages of their treatment could approach even better the issues of the dynamicity of this concept.

The amount of questionnaires designed to assess the QOL reflects the fact that there is no questionnaire that can cover all domains compromised in the HNC. Each health service chooses to apply the questionnaire that they consider to be more complete and appropriate to their questions and that will give the answers sought, and some services also prefer to apply at least two of them, as a way to contemplate the greatest amount of domains. Attention to the population to which the questionnaires are applied is an important factor to be considered because, although they are self-applicable, all participants had difficulties in

performing the assessment on their own and needed help to answer them and an interlocutor to discuss what they believed to be necessary. Therefore, we believe that it is essential to consider in the scoring the comments given by the subjects.

## ■ FINAL CONSIDERATIONS

Of the quality of life (QOL) questionnaires evaluated, the EORTC QLQ (H&N) proved to be the most specific questionnaire for speech questions, while the UW-QOL further explores the physic questions and the FACT (H&N) better covers the emotional/psychological domain. Population studies make it impossible the application of interviews; this way, questionnaires continue to be the best option. On the other hand, when the aim is to promote the best ‘listening’ to the patient, the interview can bring important information and better reveal the dynamism of the QOL in the life of a subject.

We believe that to attain a gold standard in the assessment of the QOL, the association of several instruments is required, such as questionnaires, interview and clinical evaluation, in order to know as much as possible the real needs of the patient in order to promote an improvement of their QOL in different domains (functional, social and emotional).

## RESUMO

**Objetivo:** verificar a contribuição dos diferentes questionários e de entrevista na avaliação de qualidade de vida em sujeitos laringectomizados totais que se comunicam pela voz esofágica. **Métodos:** estudo quantitativo e qualitativo baseado na realização de entrevista aberta e aplicação de questionários específicos para câncer de cabeça e pescoço – UW-QOL, FACT (H&N) e EORTC QLQ (H&N35) – em quatro pacientes com idade entre 62-68 anos, submetidos à retirada total da laringe e que estão em acompanhamento fonoaudiológico para aquisição de voz esofágica. **Resultados:** a entrevista possibilitou a melhor ‘escuta’ do paciente, no entanto, quando se trata de estudos populacionais sua aplicação se torna inviável, sendo os questionários ainda a melhor opção. O EORTC QLQ (H&N) demonstrou ser o questionário mais específico para questões fonoaudiológicas, enquanto o UW-QOL explora mais as questões físicas e o FACT (H&N) aborda melhor o domínio emocional/psicológico. **Conclusão:** os questionários e a entrevista avaliados apresentaram especificidades e contribuem para a avaliação da QV de maneira diferente. Por isso, conhecer os domínios prevalentes nos questionários e a temática abordada na entrevista permite a escolha criteriosa do instrumento de avaliação de qualidade de vida mais adequado a ser aplicado ao sujeito laringectomizado total.

**DESCRITORES:** Fonoaudiologia; Qualidade de Vida; Laringectomia; Questionários

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