

Quality of life and deglutition after total laryngectomy

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SUMMARY

Introduction: Total laryngectomy creates deglutition disorders and causes a decrease in quality of life

Aim: To describe the impact of swallowing and quality of life of patients after total laryngectomy.

Method: A case series study. Patients completed a Swallowing and Quality of Life questionnaire composed of 44 questions assessing 11 domains related to quality of life (burden, eating duration, eating desire, frequency of symptoms, food selection, communication, fear, mental health, social functioning, sleep, and fatigue). The analysis was performed using descriptive statistics, including measures of central tendency and variability.

Results: The sample comprised 15 patients who underwent total laryngectomy and adjuvant radiotherapy. Of these, 66.7% classified their health as good and 73% reported no restrictions on food consistency. The domains “communication” and “fear” represented severe impact and “eating duration” represented moderate impact on quality of life. The items with lower scores were: longer time to eat than others (domain “eating duration”), cough and cough to remove the liquid or food of the mouth when they are stopped (domain “symptom frequency”), difficulties in understanding (domain “communication”) and fear of choking and having pneumonia (domain “fear”).

Conclusion: After total laryngectomy, patients report that swallowing issues have moderate to severe impact in “communication,” “fear,” and “eating duration” domains.

Keywords: quality of life; laryngeal neoplasms; laryngectomy; deglutition; deglutition disorders.

INTRODUCTION

Recent proposals for treatment of advanced cancer of the larynx emphasize more conservative approaches and make the definition of treatment an even more complex (1). However, total laryngectomy is still frequently adopted in such cases and questionnaires on health conditions and quality of life have been recommended as key promoters of success of treatment planning (2).

After total laryngectomy, oropharyngeal dysphagia can compromise the quality of life by requiring the modification of eating habits, affect socialization, and lead to a degree of isolation in activities with family members (3). Oropharyngeal dysphagia is a common symptom in patients with tumors in the head and neck regions (4) and its etiology may be related to how surgical technique

would be used, adjuvant treatments such as radiotherapy and chemotherapy, and comorbidities such as advanced age and depression (5, 6).

The impact of difficulty in deglutition in quality of life of total laryngectomized has been assessed using generic instruments (3,7-9) or instruments specific to this function (2,10,11). The results of these studies indicate that the overall quality of life after total laryngectomy is approaching the standard of the general population, as opposed to specific domains such as deglutition, which often appear associated with negative aspects (8). Nevertheless, the results are still preliminary, especially owing to the multiple number of existing instruments and because dysphagia is still underdiagnosed in this group of patients (5). The aim of this study was to describe the effect of deglutition in quality of life of patients undergoing total laryngectomy.

METHOD

The participants included patients undergoing treatment for esophageal speech acquisition at the Department of Speech Therapy in a cancer referral center located in Pernambuco, northeastern part of Brazil. We included patients who underwent total laryngectomy with neck dissection and postoperative radiotherapy, with completion of treatment for at least 3 months. We excluded patients with neurological disorders and head and neck disease and those subjected to other procedures in the head and neck.

The quality of life related to deglutition was assessed using the Swallowing Quality of Life Questionnaire (SWAL-QOL), which has been validated for Brazilian Portuguese subjects (12). The questionnaire comprises 44 questions that assess 11 domains related to quality of life (burden, feed duration, desire, symptoms frequency, food selection, communication, fear, mental health, social function, sleep, and fatigue). Each question has 5 possible answers. The answers were converted into scores ranging from 0 to 100, divided into quintiles (0 as a minimum score and 100 as a maximum positive score). In each domain, the score values regarding responses were summed and the result was divided by the number of questions in the domain, reaching the end score. The scores 0–49 were interpreted as a severe impact, 50–70 as a moderate impact, and 71–100 slight impact or no impact (10). The analysis was performed using descriptive statistics. Due to the final conversion of the SWAL-QOL results into categories (ordinal categorical variable), we used the median as a measure of central tendency and the minimum and maximum as a measure of dispersion. Among the issues addressed by the additional instrument, we herein highlight the general health status and self-reported and food consistencies accepted by the volunteer. These variables were analyzed by means of absolute and relative frequencies.

The research was submitted to the Ethics and Human Research committee and approved under the number 67/2010. The volunteers who agreed to participate in the study signed a free consent term, in accordance to Resolution 196/96 of the National Research Ethics Counsel.

RESULTS

A sample of 15 volunteers had a mean age of 63 ± 9.3 years and the following profile: male (86.7%), married (53.3%) and uncompleted elementary education (60%). The self-reported condition general health was

rated as good by a significant percentage of volunteers (Graphic 1).

Graphic 2 shows that most participants described the consistency of the food consumed in the last week as difficult to chew. No volunteer used any alternative feeding method at the time of data collection.

Table 1 shows the distribution of SWAL-QOL domains, according to the median. It was observed that the “communication” and “fear” domains were those with the lowest scores, indicating severe impact on quality of life related to deglutition. The “feeding duration” domain caused moderate impact and the others domains caused discrete impact or no impact.

The descriptive analysis (Chart 1) of data revealed that items with higher absolute and relative frequency of responses with scores between 0 and 50 were longer time required to eat (53.3%; “feeding duration” domain), cough to remove the liquid or food out of the mouth when they are standing (40% and 46.7%, respectively, “frequency of symptoms” domain), difficult to understand (46.7%; “communication” domain), and fear choking and having pneumonia (40% and 53.3%, respectively; “fear” domain).

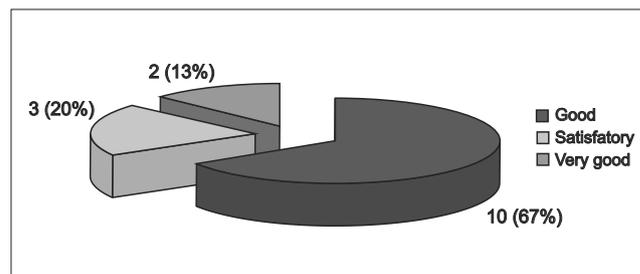


Chart 1. Overall health condition self-reported by patients with total laryngectomy. Quality of life relation to deglutition, Recife, 2011.

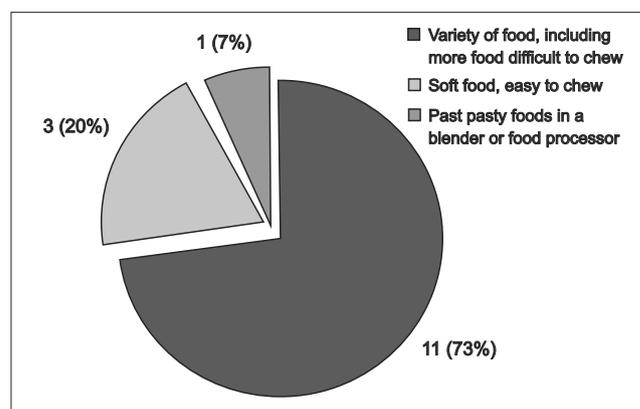


Chart 2. Graph of consistency or texture most common last week. Quality of life related to total laryngectomized deglutition, Recife, 2011.

Table 1. Distribution of variables related to SWAL-QOL domains, according to measures of central tendency and variability. Deglutition quality of life related to total laryngectomy. Recife, 2011.

Variable	Median	Minimum–Maximum
De-glutition as a burden	100	0–100
Feeding duration	50	0–100
Desire to eat	75	16.6–100
Symptoms frequency	80.3	37.5–96.4
Food selection	100	50–100
Communication	37.5	25–37.5
Fear	43.7	25–43.7
Mental health	95	70–95
Social function	95	25–95
Sleep	75	37.5–75
Fatigue	83.3	50–83.3

DISCUSSION

In Brazil, a group of researchers published 2 studies in which the SWAL-QOL questionnaire was used in patients after a total laryngectomy in São Paulo; however, unlike the present study, they found only a moderate impact of deglutition on quality of life (10,11).

In one of these studies, 12 patients with total laryngectomies answered the questionnaire. In this sample, the domains that resulted in the lowest median values were “communication” and “desire for food,” whose impact was moderate on the quality of life. It is worth noting that the “feeding duration” domain was not considered in this study. In the other work with a sample of the same health service, the lowest median found in the “feeding duration” and “communication” domains, with moderate impact on quality of life (11).

It is noticed that the “communication” domain is always present and associated with negative aspects. The permanent loss of laryngeal voice and the difficulties of adapting to alternative communication can support this result (13). The fact that the volunteers of this research are not yet fully adapted to esophageal speech may have influenced the result. In the institution where the collection was made, the esophageal voice was the method of communication rehabilitation, since the other possibilities of more sophisticated vocal rehabilitation (tracheoesophageal and laryngeal electronic prostheses) require costs that are not compatible with the profile of low-income users of this service.

We emphasize that the individual variations in relation to culture, beliefs, religions, social, economic,

professional, and family situations (10) can exert a strong influence on the perception that the individuals have of their quality of life. Thus, the differences and similarities between our study and others may possibly be explained by the variable aspects of social determinants, whose importance should be further explored in future research.

The SWAL-QOL is a protocol that considers a specific functional domain; however, there are protocols that assess the overall quality of life and include deglutition (3,9).

An Australian study (3) investigated the effect of dysphagia on quality of life of 110 patients after total laryngectomy. This study used the World Health Organization Quality of Life-BRIEF (WHOQOL-BRIEF) and the University of Washington QOL (UW-QOL). There was no difference between the findings of the subjects with and without dysphagia; however, total laryngectomy with dysphagia had more functional impairment, reduced social participation, and higher levels of depression and anxiety. The authors conclude that although dysphagia does not directly determine the quality of life after total laryngectomy, it can have a negative impact on functional and psychological well-being of the patient.

In another study (8) in patients with total laryngectomy with more than 2 years of completion of treatment, the overall quality of life did not differ from that of the general population, but there was adherence to specific scales of the physical domain, which is influenced by age, sex, radiotherapy, and chemotherapy. In the sample of these authors, women reported more difficulties with deglutition, which corroborates the findings of another study (14). Because of our small sample size, we did not compare the results by gender.

When considering the patient’s perspective regarding the impact of total laryngectomy on quality of life, a qualitative study (15) received reports of psychological and functional problems, including dysphagia. The authors highlight the high number of difficulties reported even after end of treatment and reinforce the need for maintenance of the monitoring team of multidisciplinary rehabilitation for longer periods after surgery.

About this, the literature says that the longer survival is not an accurate reflection of the success of treatment and does not necessarily indicate better quality of life (2). Therefore, there is a need to stimulate a long-term care to these individuals and to promote the application of more reliable instruments that can capture the impression of the subject with respect to their quality of life.

For longer-term evaluations, the Performance Status Scale for Head and Neck Cancer Patients (PSS-HN) was

Table 2. Distribution of the sample of patients with total laryngectomy according to the responses of SWAL-QOL questionnaire (Portas, 2009) with respect to burden, feeding duration, eating desire, symptom frequency, food selection, communication, fear, mental health, social function, sleep, and fatigue domains from quality of life related to deglutition in total laryngectomy patients (Recife 2011).

RESPONSES	SCORE 0 n (%)	SCORE 25 n (%)	SCORE 50 n (%)	SCORE 75 n (%)	SCORE 100 n (%)
Deglutition as a burden domain					
Dealing with my deglutition problem is very difficult	3 (20%)	-	-	4 (26.7%)	7 (46.7%)
My deglutition problem is the major disruption in my life	1 (6.7%)	-	2 (13.3%)	-	12 (80%)
Feeding duration domain					
It takes me longer to eat than others	8 (53.3%)	-	5 (33.3%)	1 (6.7%)	1 (6.7%)
I take much time to eat my meal	5 (33.3%)	-	1 (6.7%)	-	9 (60%)
Eating desire domain					
Most days, I do not care if I eat or not	3 (20%)	2 (13.3%)	-	3 (20%)	7 (46.7%)
I'm rarely hungry	1 (6.7%)	2 (13.3%)	2 (13.3%)	3 (20%)	7 (46.7%)
I don't have more pleasure in eating	2 (13.3%)	2 (13.3%)	2 (13.3%)	1 (6.7%)	8 (53.3%)
Symptoms frequency domain					
Cough	1 (6.7%)	3 (20%)	6 (40%)	2 (13.3%)	3 (20%)
Choking when eating	-	1 (6.7%)	1 (6.7%)	4 (26.7%)	9 (60%)
Choking with liquids	-	1 (6.7%)	-	2 (13.3%)	12 (80%)
Present thick saliva or secretion	3 (20%)	3 (20%)	4 (26.7%)	1 (6.7%)	4 (26.7%)
Vomiting	-	-	-	1 (6.7%)	14 (93.3%)
Nausea	-	-	-	1 (6.7%)	14 (93.3%)
Difficulties in chewing	3 (20%)	2 (13.3%)	-	-	10 (66.7%)
Excessive secretion of saliva	4 (26.7%)	2 (13.3%)	2 (13.3%)	1 (6.7%)	6 (40%)
Hawking	2 (13.3%)	1 (6.7%)	1 (6.7%)	-	10 (66.7%)
The food stops in the throat	1 (6.7%)	1 (6.7%)	3 (20%)	2 (13.3%)	8 (53.3%)
The food stops in the mouth	-	1 (6.7%)	1 (6.7%)	-	13 (86.7%)
Food or drink drip from the mouth	1 (6.7%)	1 (6.7%)	-	1 (6.7%)	12 (80%)
Food or drink out through the nose	-	1 (6.7%)	3 (20%)	1 (6.7%)	10 (66.7%)
Cough to remove liquid or food out of the mouth when they are stopped	7 (46.7%)	-	1 (6.7%)	2 (13.3%)	5 (33.3%)
Food selection domain					
Knowing what I can and not can eat is a problem for me	3 (20%)	-	1 (6.7%)	3 (20%)	8 (53.3%)
It's hard to find foods I can and like to eat	-	-	1 (6.7%)	1 (6.7%)	13 (86.7%)
Communication domain					
People have difficulty understanding me	1 (6.7%)	7 (46.7%)	5 (33.3%)	-	2 (13.3%)
It has been difficult to communicate clearly	4 (26.7%)	3 (20%)	4 (26.7%)	2 (13.3%)	2 (13.3%)
Fear domain					
I'm afraid of choking when I eat	6 (40%)	1 (6.7%)	2 (13.3%)	1 (6.7%)	5 (33.3%)
I worry about having pneumonia	8 (53.3%)	1 (6.7%)	1 (6.7%)	1 (6.7%)	4 (26.7%)
I'm afraid of choking on liquids	5 (33.3%)	1 (6.7%)	-	1 (6.7%)	8 (53.3%)
Never know when I'll choke	5 (33.3%)	-	-	1 (6.7%)	9 (60%)
Mental health domain					
My deglutition problem depresses me	1 (6.7%)	1 (6.7%)	2 (13.3%)	2 (13.3%)	9 (60%)
I have to be very careful when I drink or how to bother me	2 (13.3%)	-	-	3 (20%)	10 (66.7%)
I've been discouraged with my deglutition problem	1 (6.6%)	-	3 (20%)	3 (20%)	8 (53.3%)
My deglutition problem frustrates me	2 (13.3%)	-	2 (13.3%)	1 (6.7%)	10 (66.7%)
I become impatient in dealing with my deglutition problem	2 (13.3%)	1 (6.7%)	-	3 (20%)	9 (60%)
Social function domain					
I do not go out to eat due to my deglutition problem	1 (6.7%)	3 (20%)	-	-	11 (73.3%)
My deglutition problem becomes difficult to have a social life	3 (20%)	1 (6.7%)	-	-	11 (73.3%)
My job or my leisure activities changed by my deglutition problem	3 (20%)	-	-	3 (20%)	9 (60%)
Social programs and vacations do not satisfy me because of my deglutition problem	2 (13.3%)	-	-	-	13 (86.7%)
My role with family and friends has changed due to my deglutition problem	2 (13.3%)	1 (6.7%)	-	3 (20%)	9 (60%)
Sleep domain					
Have trouble sleeping?	3 (20%)	1 (6.7%)	1 (6.7%)	-	10 (66.7%)
Is that a problem to keep sleeping?	3 (20%)	2 (13.3%)	3 (20%)	2 (13.3%)	5 (33.3%)
Fatigue domain					
Do you feel weak?	-	2 (13.3%)	-	2 (13.3%)	11 (73.3%)
Do you feel tired?	2 (13.3%)	4 (26.7%)	1 (6.7%)	2 (13.3%)	6 (40%)
Do you feel exhausted?	2 (13.3%)	4 (26.7%)	1 (6.7%)	1 (6.7%)	7 (46.7%)

used to assess the degree of dysphagia before and after total laryngectomy in 20 patients (9). It was concluded that the “eating in public” and “normal diet” domains worsened in 50%, even 2 years after surgery. The result reinforces the remarkable social impact that the deglutition difficulty has after total laryngectomy (3), even after a long period after treatment. Moreover, it agrees with the results of our research that revealed a moderate impact on “difficulty eating in public” domain.

However, this same work (9), differs from ours with respect to food consistency, but not to other studies using SWAL-QOL. The percentage of subjects with restriction for solids is comparable to that found in a previous study with the same number of individuals (26.3%) (11). In another study with 12 patients, 4 had restriction (10), but these had the lowest scores, which suggests that the consistency of food interferes with quality of life (10). When considering the small number of volunteers, we decided not to make this comparison for believing that the subgroups would be uneven and the result would not be representative of the entire population.

Despite the severe and moderate impact found in some domains of SWAL-QOL, no volunteers rated their general health less than satisfactory, and previous studies have also found the same pattern (10,11). This finding can be explained by time to clinical stability at the time of answering the questionnaire. It also reveals that, despite the impact caused by deglutition difficulties, this does not interfere negatively in the context of general health from the perspective of the respondent (10,11).

The frequency of deglutition difficulties is greater when surgery is combined with radiotherapy, as observed in the treatment profile of all of our subjects. Researchers recruited 26 patients who underwent only surgery and 95 who underwent surgery combined with radiotherapy. It was found that the deglutition was better in the group whose treatment was surgical alone (14).

Unlike our current findings, those of our previous research (2) did not detect a negative impression of the patients in relation to deglutition after treatment. In that study, another specific instrument was used for assessment of dysphagia, the MD Anderson Dysphagia Inventory. This shows that the choice of the questionnaire to be applied must be judicious as well as the interpretation of data by the multidisciplinary team.

CONCLUSION

After total laryngectomy, deglutition exerted a severe impact on quality of life in terms of “communication” and

“fear” domains and a moderate impact on the “feeding duration” domain. The other domains caused discrete impact or no impact.

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