

Original articles

Voice and quality of life of totally laryngectomized patients: a comparative study

Voz e qualidade de vida de laringectomizados totais: um estudo comparativo

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ABSTRACT

Purpose: to analyze the voice-related quality of life in totally laryngectomized patients in speech therapy for a support group.

Methods: the studied population was composed of 11 totally laryngectomized subjects of both genders between 43 and 83 years of age, who speak using a tracheoesophageal prosthesis or electronic larynx. The patients answered the Brazilian Portuguese version of the Voice-Related Quality of Life (VR-QOL) questionnaire and rated their satisfaction with their communication on a 10cm visual analogic scale. Results were submitted to statistical analysis with a 5% significance level.

Results: tracheoesophageal prosthesis speakers had better results in the global score of the VR-QOL when compared with electronic larynx speakers ($p=0.026$). The subject with higher global VR-QOL scores had higher satisfaction levels regarding their communication ($p=0.001$). Satisfaction levels with communication were also statistically related to time of surgery ($p=0.05$). There were no statistically significant associations regarding satisfaction with communication and sociodemographic variables sex ($p=0.154$) and age ($p=0.303$).

Conclusion: individuals with more time since surgery are better satisfied with their communication. Satisfaction levels showed that the VR-QOL is a reliable measure of communication satisfaction of totally laryngectomized patients.

Keywords: Voice; Laryngectomy; Quality of Life; Speech, Alaryngeal

RESUMO

Objetivo: analisar a qualidade de vida relacionada à voz em pacientes laringectomizados totais participantes de um grupo de apoio.

Métodos: a população estudada foi constituída por 11 indivíduos laringectomizados totais, de ambos os sexos com idade compreendida entre 43 e 84 anos, falantes por meio de voz traqueoesofágica ou laringe eletrônica. Foi aplicado o protocolo Qualidade de Vida em Voz (QVV) e uma escala representada por uma régua de dez centímetros para aferição da satisfação da comunicação.

Resultados: os indivíduos falantes traqueoesofágicos apresentaram melhores resultados no escore global do QVV em relação aos usuários de laringe eletrônica ($p=0.026$). Os sujeitos que apresentaram melhores índices globais no QVV apresentaram melhores índices de satisfação com a comunicação ($p=0.001$). Os índices de satisfação com a comunicação apresentaram relação com o tempo de cirurgia ($p=0.050$). Não foram encontradas associações entre a satisfação com a comunicação e as variáveis sociodemográficas sexo ($p=0.154$) e idade ($p=0.303$).

Conclusão: pode-se observar que quanto maior o tempo de cirurgia mais satisfeito o indivíduo está com a comunicação. Observou-se ainda que o QVV é uma medida fidedigna da satisfação na comunicação de laringectomizados totais.

Descritores: Voz; Laringectomia; Qualidade de Vida; Voz Alaríngea

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INTRODUCTION

The larynx is an organ acting in several body functions, as it acts as a sphincter, in respiration and in deglutition, in addition to its primary role in producing the human voice. Laryngeal disorders may cause great difficulties regarding phonation, breathing and feeding¹. Laryngeal cancer corresponds to one to two percent of malignant tumors that affect humans all over the world, and is the most common type of head and neck cancer. The patients with this disease are typically male. Smoking and alcohol intake are the best established risk factors for this kind of cancer².

The treatment of a malignant tumor involves surgical procedures where either the entire larynx or parts of it are removed, total and partial laryngectomies, respectively. Total laryngectomies result in complete loss of laryngeal voice and thus, a rehabilitation method must be adopted in order to reestablish oral communication³.

Aside from losing laryngeal voice, the patient undergoing a total laryngectomy suffers several body changes due to the permanent separation of the digestive and respiratory tracts. The individual will breathe through a permanent tracheostoma that will enable air passage when inhaling and exhaling⁴.

There are two crucial moments for the laryngectomized patient in coping with diagnosis and treatment: the possibility of death, associated to cancer and fear of surgery, and the understanding of all of the changes that will take place, especially the loss of oral communication⁵.

Therefore, Speech-Language Pathology (SLP) rehabilitation is extremely important, not only to assist the learning of a method for the acquisition of a new voice, but also to reinsert the patient in their social and professional circle with good quality of life. The Speech-Language Pathologist should explain the changes in the anatomy and physiology brought on by surgery, the use of a feeding tube immediately after the procedure and the permanent presence of the tracheostoma, as well as show the patient the options of existing methods for oral communication rehabilitation after laryngectomy: esophageal voice, tracheoesophageal voice (with a vocal prosthesis) and electronic larynxes⁶.

It is therefore necessary to know each patient's individual needs, understanding that there must be an acceptance of the altered body image, the meanings associated with abstinence of tobacco and alcohol and, above all, in helping the patient choose the best vocal rehabilitation method, always aiming at the best possible quality of life for these patients.

The loss of laryngeal voice is the main complication resulting from total laryngectomy. The voice represents the individual's identity and its loss limits social interaction, and the communication of feelings, desires, as well as individual and biological characteristics. Therefore, the purpose of this study was to analyze voice-related quality of life in totally laryngectomized patients, through the level of user satisfaction with their chosen voice rehabilitation method, and how the loss of laryngeal voice and communication rehabilitation influence their quality of life.

METHODS

This is an observational, cross-sectional, quantitative study, approved by the research ethics committee at the Federal University of Santa Catarina (UFSC) under protocol number 1183216. Subject participation in the study was conditioned to signing a free-informed consent term.

The inclusion criteria were patients submitted to total laryngectomy who participated in a support group for totally laryngectomized patients (GAL) at the Oncological Research Center (CEPON) in the city of Florianópolis, Santa Catarina, who communicated using a tracheoesophageal prosthesis or an electronic larynx.

The patients were invited to participate in the study during the support group's monthly meetings. During data collection, there were 16 patients participating in the group, of which five were communicating exclusively through esophageal voice, and were excluded from the study. All other patients (11) met the inclusion criteria and agreed to participate.

The subjects were asked to fill out the Brazilian Portuguese version of the Voice-Related Quality of Life – V-RQOL protocol (Figure 1), translated and validated by GASPARINI and BEHLAU, 2009⁷ and to complete a self-assessment of their satisfaction with the voice rehabilitation method they used. This procedure involved a 10cm analogical-visual scale where 0 (zero) represented extremely dissatisfied and 10 (ten) extremely satisfied. The patient freely marked the spot on the scale that best represented his/her satisfaction at the moment of data collection. Afterwards, each mark was measured and recorded with one decimal point precision.

The V-RQOL has a list of possible voice-related problems and aims to characterize the influence of a possible voice disorder in daily life activities. It is a questionnaire composed of ten questions that must be

answered considering the severity of the problem and how often it has occurred in a period of approximately two weeks before it is being completed.

The data was collected in a silent room, with the presence of the main researcher and all participants. When needed, the questions were asked verbally, individually.

The value of the total V-RQOL score was calculated according to the following formula [Total = 100 – (raw score – 10/ 40) x 100].

The maximum score is 100 (best quality of life), and the minimum score is zero (worst quality of life).

Statistical analysis compared the variables “rehabilitation method” (tracheoesophageal prosthesis

and electronic larynx), “satisfaction with communication”, “time of surgery” (months), as well as social demographic data (age and sex) of the subjects. In order to analyze the association of these variables with the V-RQOL results the mean values of the continuous variables (age, V-RQOL score, satisfaction and time of surgery) were calculated, thus generating two categorical variables (above and below the mean) to study the association between them. This was performed using the Chi-Square test, with a significance level of 5%.

Protocolo de Qualidade de vida em Voz –QVV

Validação para o português: GASPARINI, G.; BELHAU, M. Quality of life: Validation of Brazilian Version of the- Voice- Related Quality of Life (V-RQOL) Measure of Voice, in press, 2008.

Nome: _____ Data: _____

Sexo: _____ Idade: _____ Profissão: _____

Estamos procurando compreender melhor como um problema de voz pode interferir nas atividades de vida diária. Apresentamos uma lista de possíveis problemas relacionados à voz. Por favor, responda a todas as questões baseadas em como sua voz tem estado nas duas últimas semanas. Não existem respostas certas ou erradas.

Para responder ao questionário, considere tanto a gravidade do problema, como sua frequência de aparecimento, avaliando cada item abaixo de acordo o tamanho do problema que você tem. A escala que você irá utilizar é a seguinte:

- 1 = não é um problema
- 2 = é um problema pequeno
- 3 = é um problema moderado/médio
- 4 = é um grande problema
- 5 = é um problema muito grande

Por causa de minha voz O quanto isto é um problema?

- | | |
|--|-----------|
| 1. Tenho dificuldades em falar forte (alto) ou ser ouvido em lugares barulhentos. | 1 2 3 4 5 |
| 2. O ar acaba rápido e preciso respirar muitas vezes enquanto eu falo. | 1 2 3 4 5 |
| 3. Às vezes, quando começo a falar não sei como minha voz vai sair. | 1 2 3 4 5 |
| 4. Às vezes, fico ansioso ou frustrado (por causa da minha voz). | 1 2 3 4 5 |
| 5. Às vezes, fico deprimido (por causa da minha voz). | 1 2 3 4 5 |
| 6. Tenho dificuldades em falar ao telefone (por causa da minha voz). | 1 2 3 4 5 |
| 7. Tenho problemas no meu trabalho ou para desenvolver minha profissão (por causa da minha voz). | 1 2 3 4 5 |
| 8. Evito sair socialmente (por causa da minha voz). | 1 2 3 4 5 |
| 9. Tenho que repetir o que falo para ser compreendido. | 1 2 3 4 5 |
| 10. Tenho me tornado menos expansivo (por causa da minha voz) | 1 2 3 4 5 |

Figure 1. Brazilian Version of the Voice-Related Quality of Life Protocol

RESULTS

The studied population was composed of 11 totally laryngectomized patients speaking with an electronic larynx (8) or tracheoesophageal voice (3), aged between 43 and 84 years (mean 65 ± 10.5 years). In this group, two individuals were female and nine were male, with time since surgery between 18 and 204 months (mean 75.4 ± 66.8) (Table 1).

The satisfaction levels regarding communication had mean results of 6.6cm (CI (95%) = 4.89 – 8.49) in a 10cm scale. Six individuals had results below the mean satisfaction and five of them were above the mean. All individuals who used a tracheoesophageal prosthesis were above the mean with better satisfaction indexes

Regarding the V-RQOL (Table 2), the mean of the general scores was calculated (59.5 ± 23.4) and thus, the patients were divided into categories as above and below the mean (<60 and 60+). The findings showed that six individuals were below the mean and five of them above the mean. All users of tracheoesophageal prosthesis scored above the mean with better V-RQOL scores. Table 3 shows the results for the total score and the score for each individual domain in the V-RQOL protocol.

When relating the rehabilitation method with the global V-RQOL score showed that six electronic larynx users are in the <60 category and two in the 60+ category. All tracheoesophageal speakers had results within the 60+ category, showing that the group of tracheoesophageal speakers has a better voice-related quality of life ($p = 0.026$).

The electronic larynx users reported more often as a “big problem” or a “very big problem” items such

as “I have difficulty in speaking loudly or being heard in noisy environments” as well as “I have difficulties speaking on the telephone because of my voice”.

Most of the patients using a tracheoesophageal prosthesis had lower scores on the emotional domain, referring that the items in this particular domain involving anxiety, frustration and depression represent a moderate problem. These difficulties were also reported by the patients using an electronic larynx, however, these subjects do not report avoiding social contact because of their voices, as do the patients in the first group.

When studying the association between the results of the V-RQOL with the results from satisfaction with communication, it may be seen that the level of satisfaction positively influences voice-related quality of life levels. The subjects with better global scores in the V-RQOL were more satisfied with their communication with high levels of statistical significance ($p = 0.001$).

Levels of satisfaction with communication also had statistically significant relation with time since surgery ($p=0.050$), showing that satisfaction increased with time. The subjects with more time since surgery are better satisfied with their communication. The female individuals (P5 and P11) had exactly the same time since surgery (48 months) and speech rehabilitation method (Electronic Larynx) and the smallest gross satisfaction levels found in this population (4.8 and 1.0 respectively).

There were no associations between satisfaction with communication and sociodemographic variables sex ($p= 0.154$) and age ($p=0.303$).

Table 1. Characterization of patients according to sex, age, time since surgery, rehabilitation method and level of satisfaction with communication

| Patient | Sex | Age (years) | Time since surgery (months) | Rehabilitation | Satisfaction (centimeters) |
|---------|-----|-------------|-----------------------------|----------------|----------------------------|
| P1 | M | 69 | 73 | EL | 5.7 |
| P2 | M | 67 | 24 | TEP | 9.3 |
| P3 | M | 64 | 24 | EL | 8.7 |
| P4 | M | 65 | 48 | EL | 5.3 |
| P5 | F | 64 | 48 | EL | 4.8 |
| P6 | M | 66 | 204 | TEP | 9.8 |
| P7 | M | 84 | 18 | EL | 5.4 |
| P8 | M | 73 | 120 | EL | 9.5 |
| P9 | M | 48 | 18 | EL | 5.9 |
| P10 | M | 71 | 204 | TEP | 8.2 |
| P11 | F | 44 | 48 | EL | 1.0 |

Key: M- male; F- female; EL- electronic larynx; TEP- tracheoesophageal prosthesis

Table 2. Distribution according to rehabilitation methods, mean score on the voice-related quality of life protocol and satisfaction with communication

| | n | % |
|-----------------------|---|-------|
| Rehabilitation | | |
| LE | 8 | 72.73 |
| PTE | 3 | 27.27 |
| V-RQOL | | |
| <60 | 6 | 54.55 |
| 60+ | 5 | 45.45 |
| Satisfaction | | |
| <6.7 | 6 | 54.55 |
| 6.8+ | 5 | 45.45 |

Key: EL- electronic larynx; TEP- tracheoesophageal prosthesis

Table 3. Total scores and physical and emotional domain scores on the voice-related quality of life (V-RQOL) protocol

| Patient | V-RQOL Scores (total) | Physical Domain | Emotional Domain |
|---------|-----------------------|-----------------|------------------|
| P1 | 42.5 | 37.5 | 50 |
| P2 | 75 | 83.4 | 62.5 |
| P3 | 62.5 | 62.5 | 62.5 |
| P4 | 35 | 45.9 | 18.8 |
| P5 | 35 | 29.2 | 43.8 |
| P6 | 95 | 95.9 | 93.8 |
| P7 | 52.5 | 54.2 | 50 |
| P8 | 95 | 91.7 | 100 |
| P9 | 50 | 62.5 | 31.2 |
| P10 | 85 | 75 | 100 |
| P11 | 27.5 | 25 | 31.2 |

Table 4. Characterization of the patients according to time since surgery and level of satisfaction with communication *

| Patient | Time since surgery (months) | Satisfaction (cm) |
|---------|-----------------------------|-------------------|
| P1 | 73 | 5.7 |
| P2 | 24 | 9.3 |
| P3 | 24 | 8.7 |
| P4 | 48 | 5.3 |
| P5 | 48 | 4.8 |
| P6 | 204 | 9.8 |
| P7 | 18 | 5.4 |
| P8 | 120 | 9.5 |
| P9 | 18 | 5.9 |
| P10 | 204 | 8.2 |
| P11 | 48 | 1 |

*Chi-square association test: $p=0.05$

DISCUSSION

The purpose of this study was to analyze the voice-related quality of life of totally laryngectomized patients participating in a support group. Furthermore, it investigated the subjects' levels of satisfaction with their chosen method of speech adaptation and, how the loss of laryngeal voice and their rehabilitation influenced their quality of life. It should be noted that there was a difference in the number of subjects rehabilitated with an electronic larynx (8) and tracheoesophageal prosthesis (3). This was due to the characteristics of the group where the study was conducted (convenience sample). However, the statistical analysis that predicts a 5% chance of error when considering the significance of results, allows for association analyses to be conducted between both groups of subjects.

The mean age of the participants was 65 and of all 11 individuals only two were female. Literature states that laryngeal cancer is typically related to males, associated to high intake of tobacco and alcoholic beverages, malnutrition, exposure to toxic and chemical substances and family history of cancer. The estimated incidence is 7640 new cases per year, where 6870 are men and only 770 are women⁸.

The satisfaction with communication was well distributed, as six patients had results below the mean and five above it (6,6 cm). In spite of the reduced sample, all tracheoesophageal speakers had values above the mean. These results were expected since tracheoesophageal voice uses air coming from the lungs, and thus increases maximum phonation time, enables better speech fluency and variation of intensity and modulation, making the resulting voice closer to natural standards¹. However, two subjects (P3 and P8)

who were electronic larynx speakers had results above average, which may have happened due to their having adapted to this rehabilitation method and are thus satisfied with their communication.

Regarding voice-related quality of life, the results show that, when considering the mean total scores (59.5), six individuals once again scored below the mean and five above the mean. The subjects with tracheoesophageal prosthesis had the best V-RQOL scores. These data are similar to other studies^{9,10} that show that tracheoesophageal speakers have better V-RQOL scores when compared to speakers with electronic larynxes and esophageal voices.

This study analyzed speakers using electronic larynx and tracheoesophageal prosthesis since these are the most commonly used speech methods in the studied support group, where esophageal voice is seldom used. The relation of rehabilitation with the global V-RQOL scores showed that six electronic larynx speakers had levels of voice-related quality of life that were lower than the mean, and only two were above the mean. This was also found by one study¹⁰ that states that even though the tracheoesophageal prosthesis is associated with better scores than the electronic larynx, users of the later showed positive association with time since surgery. Considering these two patients (P3 and P8), one had 120 months since surgery, indicating a possibility that the satisfaction with the communication method was due to time.

The subjects who spoke using an electronic larynx had the worst performance in the physical domain, as has also been shown in different studies^{11,12}. This fact may possibly occur since the questions most frequently marked as a "big" or "very big" problem

regard speaking loudly or being heard in noisy environments, as well as difficulties speaking on the telephone. Electronic larynx speakers depend on a device that usually runs on batteries, and is a cylinder with a vibrating membrane that, when in contact with the skin on the region of the neck, transfers sound to the oral region, where it is modified by the organs of articulation and produces speech. Thus, it poses limitations regarding frequency and intensity, in addition to generating a metallic voice, many times defined as 'robotic'¹³, which may pose an important barrier, especially on long-distance communication or when speaking in noisy environments.

Tracheoesophageal speakers had worst scores on the emotional domain, which shows that the items involving anxiety, frustration and depression represent a moderate/medium problem. This is justifiable since albeit using a prosthesis that provides better resources for communication such as using air from the lungs during speech, total laryngectomy is a surgery that has permanent consequences and changes¹⁴. Using a tracheostoma, the loss of laryngeal voice, in addition to the impossibility of immersion in water are reasons that, albeit physical, may harm the emotional domain of the V-RQOL. These are inherent aspects to total laryngectomy and are a reality for all patients undergoing this procedure, no matter which speech method is chosen afterwards. However, these consequences are perceived differently by tracheoesophageal prosthesis users and electronic larynx users, since the frustrations manifest in bigger damage on the physical domain for the first group of patients and in the emotional domain for the second. Two of the three tracheoesophageal users have been operated for 17 years, as shown in Table 1. It may be thought that this longer period has allowed for the physical changes brought about by surgery to be overcome or for the individual to adapt, and left scars that were expressed as frustrations when dealing with the questions in the instrument. It is also known that some of the electronic larynx users do so due to failure in using other communication methods, which may demand more time for the physical difficulties with communication to be overcome.

Furthermore, there is difficulty in social life, due to judgements, lack of sensitivity and understanding, sometimes forcing the laryngectomized patient to avoid situations that may confront him/her with these limitations¹⁵. It may also be noted that complaints such as difficulties in "speaking loudly" and "being understood in noisy environments" may be common

to all laryngectomized patients, but are many times accentuated by the limitations offered by some kinds of electronic larynxes¹⁶.

The level of satisfaction with communication positively influences the levels of voice-related quality of life. This is an important finding that shows that the V-RQOL instrument is a very accurate measurement of communication satisfaction for totally laryngectomized patients. Thus, it may be said that the better the patient's satisfaction with his/her communication, the higher V-RQOL global scores. This result is in accordance with the findings of another study¹⁷ that observed that, in spite of the irreplaceable quality of the larynx, most individuals using a tracheoesophageal prosthesis for rehabilitation have better quality of life levels and are therefore more satisfied with their communication. This is also suggested in the present study that shows statistically significant association between time since surgery and satisfaction with communication, even with only three patients using a tracheoesophageal prosthesis.

It has also been observed that the longer the time since surgery, the more satisfied the subject is with his/her communication ($p=0.050$) (Table 4). This may possibly occur since the individual gradually acquires assurance and self-confidence that lead to better satisfaction with new ways to communicate. Mourning the loss of laryngeal voice takes time. In addition, there is also mourning regarding the loss of the other functions of the larynx (sphincter, respiration, deglutition) and the needed adaptations in order to cope with the loss of this organ¹⁷. Furthermore, there may be pain and psychological conditions such as fear of death and coping with cancer that take time to be overcome¹⁸.

Another study¹⁹ states that there may be feelings such as fear, preoccupation and guilt. However, as the disease follows its course, the patients learn to overcome these feelings and, depending on the phase of life in which they are, this aspect have little or no influence on quality of life. In the beginning of the rehabilitation period, or immediately after surgery it is therefore common that people have low satisfaction rates regarding their communication. As time goes by and with greater self-assurance regarding their physical and psychological conditions, the patient will be more satisfied with his/her chosen voice adaptation method and, consequently, will have better quality of life.

It should be noted that this study was conducted with a reduced sample, excluding esophageal speakers due to the characteristics of the center where

it was conducted. Future studies should be held with a greater number of subjects in order to compare the data and also to include esophageal speakers as well as those individuals without any oral communication method of rehabilitation.

CONCLUSION

The findings of this study show that tracheoesophageal prosthesis users had global scores above the sample's mean on the V-RQOL. Association between the V-RQOL and satisfaction with communication showed that the V-RQOL is an accurate measurement of the satisfaction of communication of totally laryngectomized patients. All individuals above the satisfaction mean remained above the mean global V-RQOL scores. The longer the time since surgery, the more satisfied the individual is with his/her communication.

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