# Use of alternative communication technology on quality of life evaluation of head and neck neoplasms patients<sup>1</sup>

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Abstract: Introduction: Communication, social interactions and health-related quality of life (HRQoL) of the person affected by head and neck cancer (HNC) are affected by both diagnosis and treatment. Objective: The aim of this study was to evaluate the use of alternative communication software as a resource for the application of HRQoL assessment tools for people with HNC who underwent laryngectomy. Method: An exploratory, cross-sectional study with 100 adult individuals of both genders. A Sociodemographic identification form was used and the Brazilian Criteria for Economic Classification was applied the Functional Assessment of Cancer Therapy-Head and Neck-FACT-H&N scale. These instruments were inserted, in their original format, into the alternative communication software Livox®, which is an auxiliary communication resource that favors the communication of people with speech difficulties providing a conversion of text into sounds. Results: The dimensions of functional well-being and emotional well-being were the most affected in the evaluation of HRQoL. Most interviewees did not have difficulty in using Livox® to respond to the questionnaires. However, there was an association between the age and professional activity in relation to the use of the software, since 100% of the over-58s and non-active retirees reported some difficulties in their use. Conclusion: The use of technological resources may facilitate access to services and treatments by laryngectomized individuals, however, the elderly present greater difficulties in the use of modern communication technologies due to sociocultural contexts, cognitive and emotional difficulties. Occupational therapy can facilitate this adaptation through the use of resources, strategies, and techniques for the use of technology instruments as facilitators for communication in intra- and extra-hospital contexts, providing autonomy and independence for the subjects.

Keywords: Head and Neck Cancer, Alternative Communication, Laryngectomy, Technology in Health.

# Uso de tecnologia de comunicação alternativa na avaliação da qualidade de vida de pacientes com câncer de cabeça e pescoço

**Resumo:** Introdução: A comunicação, as interações sociais e a qualidade de vida relacionada à saúde (QVRS) da pessoa acometida pelo câncer de cabeça e pescoço (CCP), são afetadas tanto pelo diagnóstico como pelos tratamentos. Objetivo: Avaliar o uso de um software de comunicação alternativa como recurso para aplicação de instrumentos de avaliação da QVRS de pessoas com CCP, submetidas à laringectomia. Método: Estudo exploratório, transversal, realizado com 100 pessoas adultas, de ambos os sexos. Foi utilizada uma ficha de identificação Sociodemográfica e foram aplicados o Critério de Classificação Econômica Brasil e a escala *Functional Assessment of Cancer Therapy - Head and Neck – FACT – H & N.* Esses instrumentos foram inseridos, em seu formato original, no software de

**Corresponding author:** Cristiane Gomes-Ferraz/Marysia De Carlo. Departamento de Ciências da Saúde,, Faculdade de Medicina de Ribeirão Preto, Universidade de São Paulo, Av. Bandeirantes, 3900, Monte Alegre, CEP 14058-190, Ribeirão Preto, SP, Brasil, e-mail: crissgomes@live.com Received on Aug. 5, 2018; 1<sup>st</sup> Revision on Sept. 30, 2018; 2<sup>nd</sup> Revision Nov. 10, 2018; Accepted on Nov. 21, 2018. comunicação alternativa Livox®, que é um recurso auxiliar de comunicação que favorece a comunicação de pessoas com dificuldades na fala, fornecendo uma conversão de texto em sons. Resultados: As dimensões do Bem-Estar Funcional e Bem-Estar Emocional foram as mais comprometidas na avaliação da QVRS. Os entrevistados, em sua maioria, não demonstraram dificuldade em utilizar o Livox® para responder aos questionários. Porém, observou-se associação entre a idade e atividade profissional exercida em relação à utilização do software, pois 100% das pessoas com mais de 58 anos e os aposentados não ativos referiram alguma dificuldade em sua utilização. Conclusão: O uso de recursos tecnológicos pode facilitar acessos à serviços e tratamentos por parte das pessoas laringectomizadas, mas os idosos apresentam maiores dificuldades no uso de tecnologias modernas de comunicação, devido à contextos socioculturais, dificuldades cognitivas e emocionais. A Terapia ocupacional pode facilitar essa adaptação através do uso de recursos, estratégias e técnicas de uso de instrumentos de tecnologia como facilitadores para comunicação em contextos intra e extra-hospitalares, proporcionando autonomia e independência aos sujeitos.

Palavras-Chave: Câncer de Cabeça e Pescoço, Comunicação Alternativa, Laringectomia, Tecnologia em Saúde.

#### **1** Introduction

The term "Head and Neck Cancer" is used to describe malignant tumors of the upper aerodigestive tract, which includes the oral cavity, pharynx, and larynx. This type of cancer represents approximately 5% of the cases of malignant tumors and it has the fifth position in the list of most frequent neoplasia in the world, with a worldwide incidence of 780 thousand new cases per year where 1.7% corresponds to the Brazilian population. The mortality rate is estimated at 12,300 deaths per year and the survival rate is only 40-50% of the patients diagnosed (ALVARENGA et al., 2008; COLOMBO; RAHAL, 2009; VILAR; MARTINS, 2012).

Cancer of the head and neck can present varied symptomatology, depending on the place of the tumor, and most of the time, it is found accidentally, regardless the previous appearance of specific symptoms. Laryngeal cancer is one of the most common in the region of the head and neck. About 25% of these tumors are malignant, occurring approximately six times higher in men than in women (ALVARENGA et al., 2008; INSTITUTO..., 2014). In people with laryngeal cancer, the symptoms appear earlier, usually with the appearance of hoarseness, difficulty swallowing, pain or burning. Laryngeal cancer may also be signs of dyspnea, halitosis, weight loss and, in some cases, earache (VILAR; MARTINS, 2012).

When the disease is diagnosed in the early stages, the chances of a good prognosis are almost 100%, in addition to reducing the suffering of the individual due to loss of function, mutilation, reduction of the cost of treatment and better quality of survival. However, different studies have shown that social and cultural factors are related to the delay in diagnoses (CAMPOS; DE SALLES CHAGAS; MAGNA, 2007).

Radiation therapy can be used as the first option in the treatment of people with head and neck cancer. However, depending on the location and extent of the tumor, and particularly in advanced stage tumors, standard treatment involves total laryngectomy associated with radiotherapy. Laryngectomy is the partial or total removal of the larynx, a nasal organ responsible for vocalization, which may include the thyroid cartilage, vocal cords and epiglottis, and it is associated with lymph node resection with the goal of total tumor excision (BRASIL, 2014). The procedure is to preserve the larynx and voice whenever possible, but the body changes resulting from the surgery, sometimes traumatic, lead to difficulty or inability to communicate through the laryngeal voice, being highly stressful (ALVARENGA et al., 2008).

The difficulty of verbal communication due to laryngectomy affects the social interactions, particularly for their relatives and health team. The person often feels frustrated, nervous and depressed about not being able to communicate, which can cause great discomfort (PELOSI, 2005; MOSS, 2005). When verbal communication is not possible, it is essential to use therapeutic and/or communication assistive devices to assist the person in the communication process, which can benefit both those who are unable to communicate and the team, as well as contributing for the reduction of symptoms and concerns arising from the treatment (MATOS et al., 2009).

The Alternative and Expanded Communication (CAA) specifically addresses the communication skills within the field of Assistive Technology (AT). It enables the communication through the use of gestures, sign language, facial expressions, and the use of alphabet boards or pictographic symbols and also through the use of more sophisticated systems such as voice communicators, computers and tablets. These communication systems can be auxiliary or supplementary, varying according to the need of each one (PELOSI, 2005).

Since laryngectomy causes speech impairment, the methods that allow the return to verbal/oral communication may favor a better adaptation in the post-surgical process and social reintegration. An alternative communication software can favor the active social participation of these people, allowing them to express their choices according to their wishes, and the use of these resources by partial or total patients with laryngectomy is necessary from the first postoperative days (MATOS et al., 2009; PELOSI, 2005). However, the use of Alternative and Expanded Communication Technology (AEC) is little known by cancer patients with laryngectomy.

Therefore, head and neck cancer and its treatment interfere significantly with the person's HRQOL, especially regarding speech/communication, eating, physical appearance, and psychological factors, and it is important to also consider the symptoms, coping strategies, and social systems support.

The evaluation of Health Related to Quality of Life (HRQOL) has been increasingly used to search for better alternatives for cancer treatment, even if the person does not have the possibility of treatment modifying the disease (SPITZER et al., 1981). There are many instruments developed for the evaluation of QOL in health and the impact of the disease on individuals, starting from a multidimensional construct that evaluates several factors, such as the physical, functional, psychological, social, spiritual, well-being and sexual state relevant to some chronic diseases (ASHING-GIWA, 2005).

Thus, the objective of this study was to evaluate the use of alternative communication software as a resource for the evaluation of HRQOL of people with head and neck cancer submitted to laryngectomy.

#### 2 Method

This is an exploratory study with quantitative cross-sectional methodology performed with people with head and neck cancer, attended at the Head and Neck Surgery outpatient clinic of a public, tertiary, university hospital located in the interior of the state of São Paulo from April to September 2015. It was approved by the Ethics and Research Committee (CEP) of the University of São Paulo at Ribeirão Preto College of Nursing - EERP-USP under opinion nº 960.930, Protocol CAAE: 39100814.9.0000.5393 and the CEP of HCFMRP -USP, in compliance with Resolution CNS 466/12. The study group was 100 adult individuals, both men and women, diagnosed with head and neck cancer, divided into two groups: Study Group 1 (G1) with 50 patients with laryngectomy and Study Group 2 (Control Group) (G2) with 50 patients with non-laryngectomy, meeting the following inclusion criteria: Both Groups: Minimum age of 18 years old; have a diagnosis of head and neck cancer; being in outpatient treatment at the Head and Neck Surgery Clinic of HCFMRP-USP; have had previous contact with technological devices (smartphones, tablets, computers). The inclusion criterion in G1 was to have performed partial or total laryngectomy and in G2 was to have not performed total or partial laryngectomy.

After the clarification and signing the ICF, sociodemographic data were collected through an identification form; the patient's clinical data regarding cancer and its treatment were collected from the medical record. Then, the Brazilian Economic Classification Criterion (CCEB) was applied to determine the economic class and the one that is a multidimensional instrument that evaluates the HRQOL.

The evaluation of HRQOL was performed using the FACT - H&N scale - Functional Assessment of Cancer Therapy-Head and Neck (version 4.0), which includes the FACT G questionnaire and its specific module for head and neck cancer (H&N). This questionnaire shows sensitivity to evaluate people with cancer in the acute phase of treatment or late. It is self-applicable and includes 5 subscales: Physical Welfare (PWF); Social/Family Welfare (SFWF); Emotional Welfare (EBF); Functional Welfare (FBF) and; Additional specific concerns about head and neck cancer.

The general final scores are divided into three scores:

- FACT-G total score: encompassing the general sum of physical, socio-familial, emotional and functional scores;
- FACT-H&N Total score: it is the total sum score of the PWF, SFWF, EBF, FWF, and Additional Concerns scores and,
- FACT-H & N TrialOutcome Index (TOI): is the final total index of the PWF, EBF, FWF and Additional Concerns scales.

Each item is numerically punctuated, using the Likert scale from 0 to 4, obtainING final scores of the subscales and totals of the global scales. The higher

the score, the better the QOL (VARTANIAN et al., 2007).

The FACT-H&N instrument was inserted in its original form in the Livox<sup>®</sup> (LIVOX, 2013) alternative communication software to perform the data collection in this study, used as an auxiliary technological resource that favors the communication of people with speech difficulties, providing a conversion of text and images in sounds, aiming at a better autonomy of the participant before the application of the scale that evaluates their quality of life. This allowed the individual to answer the QOL assessment questionnaire alone and could still use it as a resource for better interaction with the researcher.

Livox<sup>®</sup> was installed on a tablet, and pre-defined screens were created with the CCEB and FACT H&N scales in their original form, by domains, to be answered by the interviewees. This form of presentation in the application allowed the interviewee's access and responses to the content of the scale without interference from the researcher.

The software and its way of use were explained to the interviewees some minutes before starting the collection, aiming at a previous familiarization with the software. By selecting the domain to be answered, Livox<sup>®</sup> converted the phrases into sounds and opened the new page of the scale so the person could see all the questions included there. Finally, when selecting the question, the interviewee was directed to the last page, where the Likert scale was 0 to 4, for options of answers. After answering each question, the respondent clicked the "Back" button to be directed to the previous page and so on as shown in Figure 1.

A pilot study was conducted with four people with head and neck cancer, with a laryngectomy, undergoing treatment at the HCFMRP-USP Head and Neck Surgery Outpatient Clinic. This stage allowed the researcher to train on the proposed instruments, to observe the level of understanding of the participants, to establish the size of the sample and to design the average time required to perform the data collection. It was identified that some individuals presented difficulties in using the alternative communication software, reporting lack of knowledge related to the use of the tablet and insecurity when handling it. A person could not select the answers because of illiteracy. Thinking about these issues, the inclusion criteria of this study were changed, including the item: "Have already had some contact with technological devices? (Smartphones, Tablets, computers)", seeking a better adaptation to the research participants.

All interviews for data collection were performed by the same researcher and during the whole period, there was the presence of a companion or family member. Thus, the researcher was sit next to the person interviewed, who could choose to hold or not the tablet and go clicking on the answers that appeared on the screen. The mean time of application of the questionnaires with subjects was 25 minutes.



Figure 1. Image of the Livox<sup>®</sup> pages where the FACT-H & N scale sessions were inserted.

#### 3 Data Analysis

The qualitative variables (sociodemographic and clinical) were compared with the Livox® groups using Fisher's exact test. The Mann-Whitney and Kruskal-Wallis tests were used to compare the groups on the number of cycles of chemotherapy and Livox® and analysis of covariance (ANCOVA) was proposed for the comparisons between the Livox® groups and the FACT-G and FACT-H. All models were adjusted for age, religion, education, economic class, activity, radiotherapy, chemotherapy, and metastasis (possible confounding factors). Analyzes were through SAS 9.0 software and a significance level of 5% was adopted for all comparisons. People from both groups were matched according to gender, age, education level, and economic class, according to the CCEB to reduce possible biases in the research when comparing data from G1 to G2.

#### 4 Results

The sample consisted predominantly (80%) of men in both groups (G1 and G2), aged 59-74 years old, married and coming from the cities of the Regional Health Division of Ribeirão Preto (DRS) XIII. The activity level showed that 86% of the G1 sample and 66% of G2 were retired and did not perform any paid activity, and the prevalence was of middle-low economic classes (C1 and C2), according to the CCEB.

Alcohol and tobacco use results indicated that in both groups, most of them used tobacco (94% G1 and 76% G2) and alcohol (78% G1 and 80% G2) before the diagnosis. The predominant location of the tumor was in the Larynx (90%) between the G1 and mouth region (32.0%) in the G2 and clinical staging showed that most of the individuals were classified in clinical stages III (52% of G1 and 46% of G2) or IV (48% of G1 and 28% of G2) (Table 1).

Regarding the functional characteristics of the subjects interviewed, there were factors such as use of tracheostomy, types of communication and need for assistance in activities of daily life (ADLs) such as bathing, toilet use, dressing, feeding, functional mobility, personal hygiene, and self-care.

There were 96% of the people who composed the G1 with tracheostomy (provisional or definitive), 80% with difficulty communicating verbally, needing help to perform this function. Of the individuals

Variables **G**1 **G**2 Total N (%) N (%) N(100%) 16 (16%) Location Mouth 0 (0%) 16 (32%) Glottis 4 (8%) 5 (10%) 9 (9%) Larynx 45 (90%) 6 (12%) 51 (51%) Tongue 0 (0%) 8 (16%) 8 (8%) Soft palate 1 (2%) 5 (10%) 6 (6%) Other CCP\* 0(0%)18 (36%) 18 (18%) Stage I Staging Level 0 (0%) 3 (6%) 3 (3%) Stage II 0(0%)10 (20%) 10 (10%) Stage III 26 (52%) 23 (46%) 49 (49%) Stage IV 24 (48%) 14 (28%) 38 (38%) Last Treatment Radiotherapy 32 (64.0%) 29 (58%) 61 (61%) Chemotherapy 17 (34%) 16 (320%) 33 (33%) Laryngectomy 50 (100%) 0 (0%) 50 (50%) Tracheostomy\*\* Yes 48 (96.0%) 17 (34.0%) 65 (65%) No 2 (4.0%) 33 (66.0%) 35 (35%) Communication without No 40 (80.0%) 18 (36.0%) 58 (58%) help 10 (20.0%) 32 (64.0%) 42 (42%) Yes Laryngeal Voice 0 (0.0%) 31(62.0%) 31(31%) Communication Type Esophageal Voice 39 (78.0%) 1(2.0%) 40 (40%) 2(4.0%) 0 (0.0%) Tracheoesophageal Prosthesis 2 (2%) Writing and/or Gestures 9 (18.0%) 18 (36.0%) 27 (27%)

 Table 1. Characterization of the sample according to clinical variables: location, treatments performed and functional characteristics.

\*Including Malignant Neoplasm of the regions: Tonsil, Parotid Gland, Thyroid Gland, Nasopharynx, Oropharynx and Lips. \*\*Definitive and/o Provisional. needing help, 8 (16%) of the G1 and 7 (14%) of the G2 indicated the spouse as the primary caregiver for the provision of such care.

The means were 82.7 points for the G1 and 79.9 points for the G2 showing that people in both groups assessed as satisfactory their overall quality of life (FACT-G Total score). In the TOI (FACT-H & N TrialOutcome Index) which is the final total index of the PWF, EBF, FWF, and Additional Concerns scales, the averages were 65.3 for G1 and 66.9 for G2. As for the quality of life-related to head and neck cancer (FACT-H & N Total score), the mean is 105.9 for G1 and 106.7 for G2. The most affected functions in both groups were: emotional welfare (mean of 18.6 in G1 and 18.2 in G2) and functional welfare (mean of 19.1 in G1 and 17.6 in G2).

Regarding the use of the Alternative Communication Resource - Livox<sup>®</sup> as a facilitator for the collection of the HRQOL data of the people interviewed, at the end of the collection, the following question was asked for each individual: "Did you have difficulties to use this instrument (Livox<sup>®</sup>)?" The answers were divided into three categories: Yes/More or less/No. The results will be presented in Table 2:

In general, people from both groups had no difficulties while using the resource presented. In G1, only 6% reported having difficulty with the software, while in G2 10% of the participants reported having been difficult to use Livox<sup>®</sup>.

The socioeconomic and clinical data and its relation to the use of Livox<sup>®</sup> were compared to better explore the use of this resource (Table 3), and among those who presented more or less difficulties in their use, 80% were between 59 and 74 years old. This difference was statistically significant (p=0.03) when compared to the age groups categorized in this study. There is also a difference in the activity performed by the people, in which, among those who declared to be non-active retirees, 80% reported having difficulty and 77.9% had no difficulty at any time during the software use (p=0.04).

When comparing the use of Livox<sup>®</sup> with the clinical and functional data of people from both study groups, there were no statistically significant differences, but it was observed that 73.3% among the people who underwent chemotherapy treatment

presented more or less difficulty during the use of Livox<sup>®</sup>. Among those who had verbal communication skills preserved, 62.5% reported difficulty in using the resource and of those who did not communicate without help, 80% mentioned having some difficulty during the use of the resource.

Regarding the total FACT-H&N scores, the results show that there is a relationship between "emotional welfare" and the difficulty in using Livox<sup>®</sup>. These results are presented in Table 4:

### **5** Discussion

Communication is a basic necessity and an essential factor of the human condition. It is a process of understanding and sharing messages sent and received, which enables the integration of the person into the environment in which he lives. The verbal communication is given by the words expressed by speech or writing and integrates the individual in the medium, the voice can express intentions, emotional state and physical state of the person, giving him autonomy in his information; the non-verbal refers to gestures, silence, body posture, facial expressions and others (MELLES; ZAGO, 2001; JORGE; GREGIO; CAMARGO, 2004).

In the hospital context, a significant number of patients requiring health care are permanently or temporarily unable to communicate. The need for interventions such as tracheostomy, orotracheal intubation or head and neck surgeries may lead to transient or definitive communication difficulties, and this condition hinders their relationship with the team and may lead to diagnostic difficulties (PELOSI; GOMES, 2017).

Laryngectomy causes speech impairment, and sometimes leads to symptoms and difficulties that directly affect the subject's life, even making HRQOL more difficult to assess, since the instruments used to assess quality of life are developed to be self-applicable, so the study participant can answer them without the interference of an interlocutor (FURIA, 2006). Bjordal et al. (1995) state that the instruments answered by the patient are more sensitive than when applied by a health professional.

<b>Table 2.</b> Comparison between groups G1 and G2 on the use of the alternative communication feature - Liv	Tabl	b	le	2		C	lo	m	ıр	a	ri	sc	)r	1	b	et	W	<i>ie</i>	e	n	Ę	<u>y</u> r	O.	u	р	s	(	f	1	а	n	d	1	C	£	2	C	)r	1	tł	ıe	e I	u	se	e	of	t	h	e	а	lt	er	n	at	iv	<i>r</i> e	С	o	m	n	ıu	n	ic	at	io	n	f	ea	tu	re	-	Li	vc	)X	®
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Did you have difficulties to use this	G1	G2	Total of cases
instrument (Livox <sup>®</sup> )?	(%)	(%)	(%)
Yes	3 (6.0%)	5 (10.0%)	8 (8.0%)
More or less	10 (20.0%)	5 (10.0%)	15 (15.0%)
No	37 (74%)	40 (80.0%)	77 (77.0%)

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	Did you have d	ifficulties to use th	nis instrument?	
Variable		(LI)		p-value
	Yes	More or less	No	
Gender				
Female	3 (37.5%)	4 (26.7%)	13 (16.9%)	0.21
Male	5 (62.5%)	11 (73.3%)	64 (83.1%)	
Age group				
27 to 42	1 (12.5%)	0 (0%)	3 (3.9%)	0.03
43 to 58	2 (25%)	0 (0%)	26 (33.8%)	
59 to 74	4 (50%)	12 (80%)	42 (54.6%)	
75 to 83	1 (12.5%)	3 (20%)	6 (7.8%)	
Marital Status				
Married	4 (50%)	8 (53.3%)	54 (70.1%)	0.08
Divorced	1 (12.5%)	1 (6.7%)	11 (14.3%)	
Single	2 (25%)	1 (6.7%)	6 (7.8%)	
Widow	1 (12.5%)	5 (33.3%)	6 (7.8%)	
Education level*				
Illiterate	2 (25%)	2 (13.3%)	2 (2.6%)	0.13
C.E.S./I.H.S.	4 (50%)	5 (33.3%)	34 (44.2%)	
C.H.S./I.H.E.	0 (0%)	1 (6.7%)	14 (18.2%)	
I.E.E.	2 (25%)	7 (46.7%)	22 (28.6%)	
C.H.E.	0 (0%)	0 (0%)	5 (6.5%)	
Activity				
Retired active	1 (12.5%)	1 (6.7%)	1 (1.3%)	0.04
Retired non-active	4 (50%)	12 (80%)	60 (77.9%)	
Non-retired, active	3 (37.5%)	0 (0%)	11 (14.3%)	
Non-retired, non-active	0 (0%)	2 (13.3%)	5 (6.5%)	
Economic class				
B1	0 (0%)	0 (0%)	3 (3.9%)	0.80
B2	1 (12.5%)	1 (6.7%)	11 (14.3%)	
C1	1 (12.5%)	2 (13.3%)	21 (27.3%)	
C2	4 (50%)	7 (46.7%)	29 (37.7%)	
D-E	2 (25%)	5 (33.3%)	13 (16.9%)	

Table 3. Comparison and analysis of socioeconomic data and use of the alternative communication resource - Livox<sup>®</sup>.

The incidence of head and neck cancer increases with age, and it is higher in people over 50 years old. The use of tobacco and alcohol simultaneously increases up to 30 times the risk for the development of cancer. Most interviewees in this study did not demonstrate difficulty in responding to the scale using the alternative communication feature proposed in this study. However, when analyzing data regarding the use of Livox<sup>®</sup> for the socioeconomic data, an association between age and use of the software was observed; 100% of people over 58 years old presented some difficulty. There was also a difference in the activity of the subjects; the non-active retirees reported some difficulty in using the software. These

data are justified by the fact that older people tend to have more difficulties in accessing new technologies.

Studies with elderly people who used an alternative communication resource similar to Livox<sup>®</sup> in their methodological procedures were not found. However, international studies were identified, showing difficulties of the elderly person when using technological resources, such as computers and tablets (CHANG; CHENG; PEI, 2014; LI et al., 2014; LEVKOFF; AN, 2014; CHEN et al., 2014; WRIGHT, 2014).

The current society has two characteristics: the fast technological development with the high use of information and communication technologies,

<sup>\*</sup>C.E.S./I.H.S.: Complete Elementary School/Incomplete High School; C.H.S./ I.H.E.: Completed High School/Incomplete Higher Education; I.E.E.: Incomplete Elementary Education; C.H.E.: Complete Higher Education.

Variable	FACT-H&N Score	Estimated difference (*)	Confiden (95	ce interval 5%)	p-value
Difficulty	Physical welfare	1.87	-1.00	4.75	0.20
with Livox®	Social/family welfare	-1.11	-3.93	1.71	0.44
(No - more or	Emotional welfare	2.72	0.58	4.87	0.01
less)	Functional welfare	-0.26	-3.97	3.45	0.89
	FACT-G total score	3.23	-5.54	12.00	0.47
	Additional Concerns	2.63	-2.06	7.32	0.27
	FACT-H&N Total score	5.86	-6.10	17.81	0.33
	FACT-H&N Trial Outcome Index (TOI)	4.25	-4.80	13.29	0.35
Difficulty	Physical welfare	1.27	-2.38	4.91	0.49
with Livox®	Social/family welfare	-1.40	-4.97	2.18	0.44
(No-Yes)	Emotional welfare	0.07	-2.65	2.80	0.96
	Functional welfare	1.73	-2.98	6.44	0.47
	FACT-G total score	1.67	-9.45	12.80	0.77
	Additional Concerns	1.02	-4.92	6.97	0.73
	FACT-H&N Total score	2.69	-12.47	17.86	0.72
	FACT-H&N Trial Outcome Index (TOI)	4.02	-7.46	15.49	0.49
Difficulty	Physical welfare	-0.61	-4.83	3.62	0.78
with Livox®	Social/family welfare	-0.29	-4.43	3.85	0.89
(more or less	Emotional welfare	-2.65	-5.80	0.50	0.10
- yes)	Functional welfare	1.99	-3.47	7.44	0.47
	FACT-G total score	-1.55	-14.44	11.33	0.81
	Additional Concerns	-1.61	-8.50	5.28	0.64
	FACT-H&N Total score	-3.16	-20.73	14.40	0.72
	FACT-H&N Trial Outcome Index (TOI)	-0.23	-13.52	13.06	0.97

<b>Table 4</b> Comparison of the difficulty of using Livov <sup>®</sup> with FACT-H & N score
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(\*) The comparisons were adjusted by group, age, religion, education level, economic class, activity, radiotherapy, chemotherapy, metastasis, and communication (possible confounding factors).

and the aging of the population. However, the marketplace often ignores the needs of older people in technological advances and they become incapable or at a disadvantage in the use of technologies (CHANG; CHENG; PEI, 2014).

Although the use of health technologies brings new possibilities, such as better access and faster delivery of services to the patient, there is a challenge when it comes to older patient, mainly due to cultural barriers such as beliefs and literacy, difficulties in understanding their state of health and psychological barriers, as fear of the complexity of modern technology (LEVKOFF; AN, 2014). These authors observed in their research that one of the main reasons for refusing to participate in their research was that they found the offered system difficult to use.

The same was observed in a study that aimed to evaluate the usability and usefulness of mobile health technologies to involve the older adults in the monitoring and management of their chronic diseases (LI et al., 2014). During 6 months, there

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were 1,317 elderly people, from 60 to 100 years old, with the highest concentration being 75 to 80 years old. It was observed that approximately 84.3% of the participants found this type of technology useful for their disease management, but 37.6% of the older adults were unable to use the resource because they found these technologies complex and difficult to use. This fact corroborates with the one presented during the pilot project of the current study when the participants also stated that it was difficult to use the presented resource.

Also, Chen et al. (2014) sought to improve the access of disadvantaged older adults with low socioeconomic and educational backgrounds to health services based on a health information technology resource. However, they observed that a large part could not participate in the program because they did not have access to computers. Barriers such as poverty, digital illiteracy, and residence in rural areas have significantly interfered with the access to technologies. The use of tablets by older adults was analyzed by Wright (2014), who concluded that this type of device offers a fast, useful and convenient way of digital access for this population when compared to computers in general. For this author, the greatest difficulties were related to gestures, tasks, and attention; people easily remembered actions such as sliding, touching, holding, dragging, but they had difficulty executing them. A feature such as "touching the screen", which is considered useful at first, was difficult to control and caused typos or unexpected changes of the selected page and the simple explanation was not enough to help them, requiring more training.

These difficulties did not emerge in this study because Livox<sup>®</sup> is a specific software of alternative communication, so it is already preprogrammed with functions that prevent this type of 'error' from the participant. However, social support or efficient support during the process of diagnosis and treatment with the older adult is commonly necessary so barriers to the use of technologies as facilitators can be removed or reduced to understand the ease and purpose of the resources (LI et al., 2014; LEVKOFF; AN, 2014).

Regarding the clinical and functional data, it was observed that the participants of this research who underwent chemotherapy treatment and who had the capacity of verbal communication preserved (G2) did not have statistically significant difficulty in using Livox<sup>®</sup> than in the group with laryngectomy (G1). G1 showed 80% difficulties regarding the use of the equipment, which may be associated with low education level and limited access to technological resources, which again corroborates with the studies presented above (CHANG; CHENG; PEI, 2014; LI et al., 2014; LEVKOFF; AN, 2014; CHEN et al., 2014; WRIGHT, 2014).

Also in the current study, most of the participants who had difficulty verbal communication had developed a particular method to communicate, such as through writing, gestures or lip reading, but none of them used a specific alternative communication resource, such as technological or a lower cost device.

In the hospital context, when the introduction of Alternative and Extended Communication (AEC) resources and services is not occurring, the basic communication of the patients with the family and the care team consists of the use of unsupported symbolic systems (KLEINPELL et al., 2009; PELOSI et al., 2014). This form of communication limits patient interaction and empowerment in the recovery process. Strategies such as lips movements and gestures, because they are not specific answers, can be misinterpreted by the interlocutor, contributing to the increase of frustration and anguish.

A study by Pelosi et al. (2014) carried out with patients with communicative difficulties observed that the limitation of verbal communication significantly affects their quality of life and causes a change that appears in daily life as a difficulty to perform some routine activity, regardless the cause of the problem being physical, cognitive, social or others.

The diagnosis and treatment of cancer bring varied changes in the daily life of both the affected person and their relatives, compromising their QOL. In general, family dependency and disorganization may occur due to role and burden changes, as well as worry and fear of death (SILVA et al., 2012). With the advancement of the disease and changes caused by the treatment, there are difficulties in the extra-hospital environment, decreasing of leisure and productivity and feelings of embarrassment (LUCA; SANTOS; BERARDINELLI, 2012).

Thus, the introduction of AEC resources can improve the quality of life in the hospital environment. The work performed in a hospital using the SF-36 questionnaire before and after the introduction of AEC information with hospitalized patients, showed that all the items on the scale had positive variations, evidencing that quality of life improved (BANDEIRA; FARIA; ARAUJO, 2011).

The re-adaptation of the verbal communication capacity favors the individual so he can exercise his autonomy, his desires, and opinions. Within the hospital context, the evaluation of Health Related to Quality of Life (HRQOL) is an important tool to seek a look at these difficulties that may arise after the treatment of several pathologies (PELOSI; GOMES, 2017).

The resources, strategies, and techniques for using technology instruments as facilitators for communication are present in the intra-hospital and extra-hospital care actions carried out by a multi-professional team. Occupational therapists have both prepared their patients for the use of these technological resources, and also use them to promote health, well-being, and quality of life. Occupational therapy uses adaptations to help people with functional losses in the accomplishment of their various occupations. Technological resources can provide more independence and autonomy to these people, broadening the range of services that can be provided by occupational therapists aiming at a better quality of life of the person (PELOSI; GOMES, 2017).

## **6** Final Considerations

The evaluation, prescription, vocabulary customization, patient and family training on the use of Alternative Communication technology resources from the preoperative period are part of the work of a health team composed of occupational therapists, speech therapists, and other professionals and can improve the communication and quality of life of patients with laryngectomy.

The results of this study demonstrated that the use of alternative communication software as a resource for the evaluation of patients with laryngectomy may favor the development of better treatment strategies for patients with head and neck cancer who present verbal communication difficulties due to laryngectomy from the conversion of text to voice, seeking a better understanding of their desires, wishes and understanding of their quality of life.

# 7 Limitations of the Study

Although an extensive review of the literature was performed, no studies were identified using an alternative communication technology similar to Livox <sup>®</sup> in conjunction with patients with laryngectomy, which could base or support the more specific findings of this study. These indicate the need for new research and future paths to be explored involving the use of alternative communication technologies in clinical practice.

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#### References

ALVARENGA, L. M. et al. Avaliação epidemiológica de pacientes com câncer de cabeça e pescoço em um hospital universitário do noroeste do estado de São Paulo. *Revista Brasileira de Otorrinolaringologia*, São Paulo, v. 74, n. 1, p. 68-73, 2008.

ASHING-GIWA, K. T. The contextual model of HRQoL: A paradigm for expanding the HRQoL framework. *Quality* of *Life Research*, Netherlands, v. 14, n. 2, p. 297-307, 2005.

BANDEIRA, F. M.; FARIA, F. P.; ARAUJO, E. B. Avaliação da qualidade intra-hospitalar de pacientes impossibilitados de falar que usam comunicação alternativa e ampliada. *Einstein*, São Paulo, v. 9, n. 4, p. 477-482, 2011.

BJORDAL, K. et al. Patient self-reported and clinicianrated quality of life in head and neck cancer patients: a cross-sectional study. *European Journal of Cancer Part B* Oral Oncology, Oxford, v. 31, n. 4, p. 235-241, 1995.

BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde. Instituto Nacional de Câncer. *Câncer de Laringe:* Diagnóstico. Rio de Janeiro: INCA, 2014. Disponível em: <a href="http://www2.inca.gov.br/wps/wcm/connect/tiposdecancer/site/home/laringe/diagnostico">http://www2.inca.gov.br/wps/wcm/connect/tiposdecancer/site/home/laringe/diagnostico</a>. Acesso em: 20 ago. 2014.

CAMPOS, J. L. G.; DE SALLES CHAGAS, J. F.; MAGNA, L. A. Fatores de atraso no diagnóstico do câncer de cabeça e pescoço e sua relação com sobrevida e qualidade de vida. *Revista Brasileira de Cirurgia de Cabeça e Pescoço*, São Paulo, v. 36, n. 2, p. 65-68, 2007.

CHANG, H. M.; CHENG, Y. T.; PEI, C. Discussion on the elderly's needs in information and communication technologies. *Gerontechnology*, Taiwan, v. 13, n. 2, p. 178-178, 2014.

CHEN, H. et al. Engaging digitally disadvantaged people. *Gerontechnology*, Taiwan, v. 13, n. 2, p. 99-100, 2014.

COLOMBO, J.; RAHAL, P. Alterações Genéticas e Câncer de Cabeça e Pescoço. *Revista Brasileira de Cancerologia*, Rio de Janeiro, v. 55, n. 2, p. 165-174, 2009.

FURIA, C. L. B. *Qualidade de vida em pacientes tratados de câncer de cavidade oral, faringe e laringe em São Paulo:* estudo multicêntrico. 2006. 101 f. Tese (Doutorado em Ciências) – Universidade de São Paulo, São Paulo, 2006.

INSTITUTO NACIONAL DE CÂNCER – INCA. *Estimativa 2014*: Incidência do Câncer no Brasil. Rio de Janeiro: INCA, 2014. Disponível em: <a href="http://www.inca.gov.br/estimativa/2014/">http://www.inca.gov.br/estimativa/2014/</a>. Acesso em: 04 ago 2016.

JORGE, M. S.; GREGIO, F. N.; CAMARGO, Z. Qualidade Vocal de Indivíduos Submetidos à Laringectomia Total: Aspectos Acústicos de Curto e Longo Termo em Modalidades de Fonação Esofágica e Traqueoesofágica. *Revista CEFAC*, São Paulo, v. 6, n. 3, p. 319-328, 2004.

KLEINPELL, R. M. et al. Improving Communication in the ICU, Advance for Respiratory Care and Sleep Medicine. 2009. Disponível em: <a href="http://respiratory-care-sleep-medicine">http://respiratory-care-sleep-medicine.</a> advanceweb.com/article/improving-communicati on-inthe-icu- 6.aspx>. Acesso em: 25 maio 2014.

LEVKOFF, S. E.; AN, N. Overcoming barriers to digital engagement among elders of Chinese cultural background. *Gerontechnology*, Taiwan, v. 13, n. 2, p. 97-97, 2014. Disponível em: <a href="http://www.gerontechnology.info/index.php/journal/article/viewFile/gt.2014.13.02.055.00/2020">http://www.gerontechnology.info/index.php/journal/article/viewFile/gt.2014.13.02.055.00/2020</a>>. Accesso em: 7 jan. 2016.

LI, P. et al. Improving digital engagement for elderly Chinese with mobile health technologies. *Gerontechnology*, Taiwan, v. 13, n. 2, p. 97-98, 2014. Disponível em: <a href="http://www.gerontechnology.info/index.php/journal/article/viewFile/gt.2014.13.02.301.00/2021">http://www.gerontechnology.info/index.php/journal/article/viewFile/gt.2014.13.02.301.00/2021</a>>. Acesso em: 7 jan. 2016.

LIVOX. Quem somos. Recife, 2013. Disponível em: <a href="http://www.livox.com.br/pt/">http://www.livox.com.br/pt/</a>. Acesso em: 12 jan. 2017.

LUCA, M. D.; SANTOS, I.; BERARDINELLI, L. M. M. Características nosológicas de clientes com câncer em

Cad. Bras. Ter. Ocup., São Carlos, v. 27, n. 1, p. 61-71, 2019

cuidados paliativos: autorrelato através da consulta de enfermagem. *Revista Enfermagem UERJ*, Rio de Janeiro, v. 20, n. 3, p. 293-299, 2012.

MATOS, R. E. et al. Dificuldades de comunicação verbal do cliente laringectomizado. *Revista Enfermagem UERJ*, Rio de Janeiro, v.17, n. 2, p. 176-181, 2009.

MELLES, A. M.; ZAGO, M. M. F. A utilização da lousa mágica na comunicação do traqueostomizado. *Revista Latino-Americana de Enfermagem*, Ribeirão Preto, v. 9, n. 1, p. 73-79, 2001.

MOSS, T. P. The relationships between objective and subjective ratings of disfigurement severity, and psychological adjustment. *Body Image*, Amsterdam, v. 2, n. 2, p. 151-159, 2005.

PELOSI, M. B. et al. Prancha de comunicação para pacientes hospitalizados. *Cadernos de Terapia Ocupacional da UFSCar*, São Carlos, v. 22, n. 1, p. 292-300, 2014. Suplemento Especial.

PELOSI, M. B. Proposta de implementação da Comunicação Alternativa e Ampliada nos hospitais do município do Rio de Janeiro. *Temas sobre Desenvolvimento*, São Paulo, v. 14, p. 47-53, 2005. PELOSI, M. B.; GOMES, C. A. Tecnologia Assistiva e Terapia Ocupacional no Contexto Hospitalar. In: DE CARLO, M.M.R.P.; KUDO, A. M. (Org.). *Terapia Ocupacional em Contextos Hospitalares e Cuidados Paliativos*. São Paulo: Editora Payá, 2017. p. 103-126.

SILVA, M. S. et al. Quality of life and self-image in patients with head and neck cancer. *Universitas Psychologica*, Colômbia, v. 11, n. 1, p. 13-23, 2012.

SPITZER, W. O. et al. Measuring the quality of life of cancer patients: a concise QL-index for use by physicians. *Journal of Chronic Diseases*, St. Louis, v. 34, n. 12, p. 585-597, 1981.

VARTANIAN, J. G. et al. Questionários para avaliação de qualidade de vida em pacientes com câncer de cabeça e pescoço validados no Brasil. *Revista Brasileira de Cirurgia de Cabeça e Pescoço*, São Paulo, v. 36, n. 2, p. 108-115, 2007.

VILAR, C. M. C.; MARTINS, I. M. Câncer de Cabeça e Pescoço. In: VIEIRA, S. C. et al. (Org.). *Oncologia Básica*. Piauí: Fundação Quixote, 2012. p. 9-22.

WRIGHT, P. Digital tablet issues for older adults. *Gerontechnology*, Taiwan, v. 13, n. 2, p. 306, 2014. Disponível em: <a href="http://gerontechnology.info/index.php/journal/article/download/gt.2014.13.02.169.00/2236">http://gerontechnology.info/index.php/journal/article/download/gt.2014.13.02.169.00/2236</a>. Acesso em: 15 jan. 2016.

#### **Author's Contributions**

Cristiane Aparecida Gomes-Ferraz: Elaboration of the text; organization of sources and analysis, correction and final revision. Gabriela Rezende: Elaboration of the text; organization of sources and analyzes, correction of the abstract. Marysia Mara Rodrigues do Prado De Carlo: Elaboration of the text; organization of sources and analysis, correction and final review. All authors approved the final version of the text.

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