

Voice-related quality of life results in laryngectomies with today's speech options and expectations from the next generation of vocal assistive technologies

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Abstract

Objectives: *To assess the voice handicap, the satisfaction with today's voice assisting methods and to identify the needs that should be addressed by new vocal assistive technologies for aphonic patients.*

Materials and Methods: *We conducted a prospective study on two samples of patients with total laryngectomy and submitted to speech therapy. Voice Handicap Index (VHI) questionnaires and qualitative (focus-groups) and quantitative (online surveys) methods were used.*

Results: *Analysis of the VHI total revealed that the esophageal and electrolarynx speakers had a moderate voice handicap, while tracheoesophageal speakers and patients without vocal rehabilitation had a severe handicap. Interview and survey data indicated that these patients have many needs which are unmet by available rehabilitation methods.*

Conclusions: *These results point out the necessity to improve current vocal assistive methods and to develop better technologies that could increase the quality of life of this patients.*

Keywords: *VHI, Aphonia, Vocal rehabilitation.*

I. INTRODUCTION

Patients who underwent total laryngectomy (surgical removal of the larynx) suffer from loss of voice, associated with a permanent tracheostomy that compromise their quality of life (QOL) [1]. The psychological consequences of this debilitating condition are related to anxiety, depression, hopelessness and passivity [2]. Loss of voice, altered swallowing and a permanent tracheostomy, have a profound effect on the patient's physical and psychological rehabilitation [3], [4]. When people lose their voice they can use devices that allow them to speak again; but these devices have a limited number of "identities" and may have a negative psychological impact on them [5]. Voice restorations may be obtained with any of three methods including esophageal speech (ES), voice prosthesis (TEP) and electrolarynx (EL) [6]. Studies show that patients who underwent total laryngectomy refuse, avoid or fail to use today's vocal assistive methods (Voice prostheses or Electro-larynx) to communicate with family and other members of society. Voice rehabilitation is one of the most difficult challenges that laryngectomized patients must overcome. The project "Mobile System for Rehabilitative Vocal assistance of patients with Surgical Aphonia" (acronym SWARA, which means "voice" in Javanese, the language spoken in Indonesia) aims to develop a new system for assisting these patients. The main purpose of this voice assistive device is to help patients with aphonia after surgery, to

communicate with others without the fear of being rejected or poorly-understood. This goal will be carried through a new interface involving smartphone technology which will synthesize an improved and customizable artificial and voice. Integration with mobile voice synthesis was carried out already. Many research groups have contributed to progress in speech synthesis [7], [8], [9]. Also, Patel developed the project called VocaliD, which offered the possibility to synthesize personalized voices for those unable to speak [10].

We have carried out a prospective study to assess the voice handicap and the satisfaction of patients with today's voice assisting methods and to identify the needs or requirements that should be addressed by a new vocal assistive technology for aphonic patients after total laryngectomy with or without vocal rehabilitation. Despite the progress made in vocal assistive technology, the quality of life in these patients is significantly affected [11], [12] and thus further improvements are still needed. Such results emerge from both qualitative and quantitative methodologies [13], that we also used for the current research study.

II. MATERIALS AND METHODS

A prospective study was carried out on 2 samples during 2013 and 2014, at the Ear, Nose and Throat Department of the Emergency County Hospital of Cluj-Napoca and the Department of Clinical Psychology and Psychotherapy, Babes-Bolyai University. We included patients with total laryngectomy, part of them being submitted to speech therapy: esophageal speech (ES), electrolarynx (EL) and tracheoesophageal voice prosthesis (TEP), for rehabilitation of alaryngeal communication.

Sample 1: Comprised of 65 patients with total laryngectomy and a part of them were submitted to oncological treatment (adjuvant radiotherapy, adjuvant chemotherapy and adjuvant concomitant chemoradiotherapy). This sample included 62 males and 3 women, with a median age of 59.15 years.

Sample 2: Comprised of 24 patients with total laryngectomy from the first sample who were available and agreed to participate to an interview or focus group or to complete an online survey focused on their needs and requirements regarding vocal assistive methods. They were in the similar age range as sample 1 and included only male participants.

We evaluated voice handicap with the Voice Handicap Index (VHI) questionnaires for the first group. VHI is a 30-item self-administered questionnaire on voice-related aspects. The statements represent three sub-domains functional, physical and emotional aspects of the voice handicap [14]. In the second group both qualitative (in-depth interviews, focus-groups) and quantitative (online surveys) methods was used to gather information. Patients from the second group were interviewed and surveyed by a team of psychologists from Department of Clinical Psychology and Psychotherapy, Babes-Bolyai University. This investigation targeted to identify how satisfied the patients are with the current vocal assistive method (if they are using one), what are the main problems that they are confronted with, and what improvements they are expecting form a new generation of assistive technologies. The answer to these inquiries were addressed in three steps: 1) in depth interviews to identify the main problems and the most stringent requirements (3 patients); 2) several focus group to expand the knowledge base and explore additional issues that should be targeted (11 patients); 3) an online survey using standardized questions meant to verify that the key needs and requirements are replicable on other patients than those that participated in face to face interviews and focus groups (10 patients). Additional data coming from caregivers (family members) was collected through focus groups and survey but was not reported here. The interview had only open questions meant to explore and understand patient's situations. The focus groups were conducted in small group (5-8 participants) and included both open questions, as well as closed answer questions and individual ratings related to their current satisfaction with available assistive methods and possible improvements that they are expecting. The online survey comprised almost exclusively standardized questions with closed answers and rating scales.

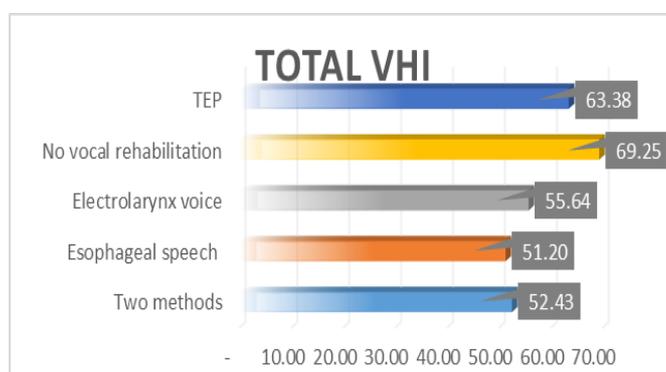


Figure 1. Analysis of the Total VHI. A low score reflects a moderate VHI, and a severe voice handicap is reflected by a total VHI score from 61.

Patients participated to individual or group discussions or filled online survey. All participants signed an informed consent form. Statistical analyses were performed using Microsoft Excel and IBM SPSS software (version 22.0).

III. RESULTS

From the 65 patients in sample 1 submitted to total laryngectomy, 24 presented no oral communication and 41 communicated with alaryngeal phonation: in 14 of them, voice rehabilitation was obtained with a voice prosthesis device, in 17 of them, learned esophageal voice, in 18 of them, with electrolarynx voice. The time since surgery until completion of the questionnaire was: between 1 month and more than 5 years.

Analysis of the VHI total revealed that the esophageal speakers group and electrolarynx speakers had a moderate voice handicap (51.20 mean score versus 55.64 mean score), and TE speakers and patients without vocal rehabilitation had a severe handicap (63.38/69.25 mean score). We found statistically significant differences between the esophageal speakers group and the group without rehabilitation, with a better score on the subscale of VHI functional mean score (19.70 mean score) for the ES group as compared with (27.54 mean score) for the patients without vocal rehabilitation, and on the emotional subscale, with a better mean score for the ES group (9.20 mean score) compared with TE speakers (19.00 mean score), and the group without vocal rehabilitation. The results from the VHI questionnaire are shown in Figure 1.

Results for sample 2 pointed out that the majority of the patients (60%) that were using a vocal assistive method (mean rating on a scale from 1 to 10, with higher values indicating higher satisfaction, was 6.43) There was high heterogeneity among the problems they reported and thus we were not able to classify them. However, based on their content, these problems can be grouped under the following categories: difficulties in being understood by the communication partners, the fact that others avoid to communicate with them, the fact that they speak much less as compared to the condition before surgery, difficulties in being heard when speaking from a considerable distance, and difficulties in being heard when there is background noise. In terms of improvements that should be addressed by future assistive methods, the patients reported that the most important functionalities they are expecting are (classification based on the mean ranking of nine options, higher values indicated better ranking): a clearer voice (6.86), a device that does not require fixation or closing a valve (6.14), a higher speaking volume (5.71), an assistive method that requires less effort when speaking (5.56), a method that allows them to speak for a longer period without interruption and a better fluency (both with a rating of 5.00). The other requirements were ranked in the lower half (see Figure 2). Finally, we asked the patients about their attitude towards possible future interfaces for a smartphone based vocal assistive method, which are both explored by the SWARA project: text-to-speech voice synthesis and real time lip-reading. Reports indicated that users are somewhat more interested in using a phone-based assistive method that integrates real time lip-reading, rather than the other option. However, both methods received average ratings that were close to the level indicating at least some level of interest (2.90 for text-to-speech and 3.60 for lip reading, both on a scale from 1 to 5). There was large variability on these ratings showing that there might be specific groups which would benefit more from one or from the other of these technologies.

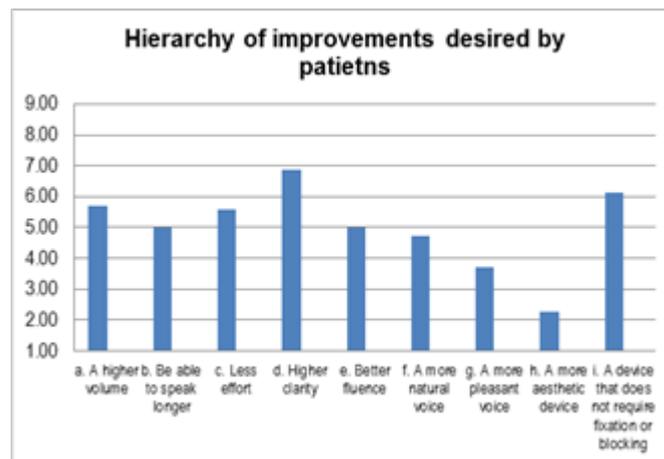


Figure 2. Average ranking for nine improvements related to vocal assistive methods that emerged from qualitative investigations. A higher score indicates that a requirement is more desired by the patients.

IV. DISCUSSION

Regarding voice rehabilitation, we found a higher score for the total VHI, functional and emotional subscales in patients with the esophageal speakers group (with a moderate voice handicap) compared with patients with TEP.

The results indicate that patients with esophageal speech had a better score than patients using today's vocal assistive devices (tracheoesophageal prosthesis and electrolarynx). This might be explained by the fact that, TEP speakers had higher expectation from the vocal assistive method (voice prostheses) than ES group. However, despite the new design of devices in recent years, obstruction of the prostheses and leakage through the devices are still the most frequent complications [15]. Compared with esophageal voice, voice prostheses require fixation and closing the valve during speech, as well as regular

changes. But esophageal speech is a learned ability that requires speech training and much practice. This indicates that there is the need to develop better assistive technologies at least for those patients that are not able to learn or use esophageal speech.

Results coming from the interviews and the survey conducted with these patients also suggest that there are still many problems and needs that are not addressed by available assistive devices. We also offered some clues about which are the main improvements they are expecting. Both interfaces proposed by the SWARA project might have a potential for at least some of the patients and each of them could cover at least some of the requirements (e.g., cleared voice, higher volume). Future studies should include larger samples to allow generalization and a clearer classification of their main problems and expected improvements. Also, future studies regarding the different interfaces of technology-based vocal assistive methods should allow the patients to test them and express their attitude based on the experience of using one or another of the communication interfaces.

V. CONCLUSION

This study demonstrated that VHI questionnaire is a useful instrument in gathering information regarding the quality of life in laryngectomized patients and is able to quantify impact of different vocal assistive methods on their functioning and adaptation to this condition. Although patients express some satisfaction towards current vocal assistive methods technology there is much space for improvements and there are many problems and needs that are not tackled by available tools.

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REFERENCES

- [1] Kapila M, Deore N, Palav RS et al., "A brief review of voice restoration following total laryngectomy." *Indian J Cancer*. 2011; **48(1)**:99-104.
- [2] Aarstad AK, Lode K, Larsen JP, Bru E, Aarstad HJ, "Choice of psychological coping in laryngectomized, head and neck squamous cell carcinoma patients versus multiple sclerosis patients." *Eur Arch Otorhinolaryngol*. 2011 Jun; **268 (6)**:907-15
- [3] Blanco-Piñero N, Antequera-Jurado R, Rodríguez-Franco L, Ibáñez-Guerra E, Herrero-Salado TF, Sánchez-Gómez S, "Emotional and psychopathological disorders in laryngectomized oncological patients." *Acta Otorrinolaringol Esp*. 2015 Jul-Aug; **66 (4)**:210-7
- [4] Sayed SI, Manikantan K, Khode S, Elmiyeh B, Kazi R, "Perspectives on quality of life following total laryngectomy." *G Ital Med Lav Ergon*. 2009 Jul-Sep; 31
- [5] Bozec A, Poissonnet G, Chamorey E, Demard F, Santini J, Peyrade F et al. , "Results of vocal rehabilitation using tracheoesophageal voice prosthesis after total laryngectomy and their predictive factors". *Eur Arch Otorhinolaryngol* 2010; **267**:751-758.
- [6] Polat B, Orhan KS, Kesimli MC et al. "The effects of indwelling voice prosthesis on the quality of life, depressive symptoms, and self-esteem in patients with total laryngectomy." *Eur Arch Otorhinolaryngol*. 2014; DOI 10.1007/s00405-014-3335-5.
- [7] Zen, H., Nose, T., Yamagishi, J., Sako, S., Masuko, T., Black, A., Tokuda, K., "The HMM-based speech synthesis system version 2.0," In: Proc.ISCA SSW6, 2007, pp. 294-299
- [8] Adriana Stan, Junichi Yamagishi, Simon King, Matthew Aylett, "The Romanian Speech Synthesis (RSS) corpus: building a high quality HMM based speech synthesis system using a high sampling rate, Speech Communication", vol **53**, pg. 442-450, 2011.
- [9] Lancioni GE, Singh NN, O'Reilly MF, Sigafoos J, Olivetti Belardinelli M, "Technology-based intervention to help persons with minimally conscious state and pervasive motor disabilities perform environmentally relevant adaptive behavior," *Cogn Process*, 2012 Aug;13 Suppl 1:S219-22
- [10] Bates M, "Voices for the Voiceless: Rupal Patel is Creating Personalized Prosthetic Voices." *IEEE Pulse*, July/August 2015
- [11] P. Farrand, and F. Duncan, "Generic health-related quality of life amongst patients employing different voice restoration methods following total laryngectomy", *Psychol Health Med*, 2007 vol. **12**, pp. 255-65.
- [12] M. Schuster, et al., "Quality of life in laryngectomees after prosthetic voice restoration", *Folia Phoniatr Logop*, 2003, vol. **55** pp. 211-9.
- [13] B.M. Op de Coul, et al., "Quality of life assessment in laryngectomized individuals: do we need additions to standard questionnaires in specific clinical research projects?" *Clin Otolaryngol*, 2005, vol. **30**, pp. 169-75.
- [14] Lundström E, Hammarberg B, Munck-Wikland E, "Voice Handicap and Health-Related Quality of Life in Laryngectomees: Assessments with the Use of VHI and EORTC Questionnaires," *Folia Phoniatr Logop* 2009; **61**:83-92.
- [15] Brown DH, Hilgers FJ, Irish JC et al., "Voice Rehabilitation:" State of the Art at the Millennium," *World J Surg*, 2003; **27(7)**:824-31.