

Voice-related quality of life: a Brazilian experience

Mara Behlau, PhD and Gisele Gasparini, MSc

Speech language pathologists, Consultants in Human Communication – Corporate SLP - “Centro de Estudos da Voz – CEV”, São Paulo, Brazil

With the great advance of medical procedures, the need of evaluating their effectiveness and benefits became a major concern in the health area. Objective measurements of evaluation solely are not enough to describe and quantify the patient's health problem. During the recent decades, the concept of health has been submitted to a deep change, incorporating patients' perception of the disease and its impact.

The World Health Organization - WHO broadened the health concept so that it could include the aspects of quality of life in its definition of complete physical, mental and social well-being¹. According to WHO, health and treatment outcome evaluation must contain not only the indicators of severity and frequency of disease, but also an estimate of well-being, which can be measured by evaluating the individual's quality of life. This organization defines quality of life as individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns^{2,3}. This is an ample concept that may be affected in many different ways according to the individual's physical health, psychological state, independence level, social relations, and personal beliefs, as well as the environment-related characteristics¹.

Quality of life evaluation is basically done by means of questionnaires, many of which developed in English and directed to the population that speaks this language. Thus, in order for these instruments to be used in other languages, they must be translated and culturally adapted based on international guidelines and have their measure properties demonstrated in a specific cultural context^{4,5}. The instrument translation must avoid literal conversion that excludes cultural and social contexts⁵. Instruments must be submitted to tests in order to have its validity, reliability and responsiveness proved. Equally, such instruments must be able to evaluate specific populations, for instance, patients with cancer, war refugees, or even certain disorders such as dysphonia⁶.

The Scientific Advisory Committee of Medical Outcomes Trust⁷ conceives and publishes guidelines to aid the development and validation of those instruments. The committee dedicates to help researchers groups around the world and analyses new instruments, whose activities have been playing an important role for the execution of scientific researches with the addressed issue.

Epidemiological and physiological measures have been traditionally used to evaluate treatment outcomes of voice deviation. In ideal conditions, a dysphonic patient evaluation includes the history, a complete laryngological and voice evaluation, including aerodynamic and acoustic measurements, the so-called vocal function tests. However, these evaluations alone are not able to quantify the patient's voice problem neither to reflect the impact of a deviated voice. Sometimes, objective evaluation of dysphonia may present normal result, while quality of life instruments and subjective analysis provide diverse information about the vocal difficulty⁸. Even if a vocal deviation could have been precisely quantified, it would not necessarily reflect the vocal disorder or the effect of its treatment is having upon the patient's life. More recently, researches showed the importance of including subjective parameters in voice evaluation. Consequently, the concept of voice-related quality of life was developed⁹ and easily adopted into the daily clinical routine. At the end of the 90's, the protocols that evaluate quality of life related to voice were introduced in Brazil, by the second author, who first brought the two widely used questionnaires: V-RQOL and VHI. From then on, many other protocols were also

introduced and others developed. Protocols need to be treated with great respect in order to do not compromise their inner construct. A simple translation can distort the aim and the result of the rough data. So, a validation process has to be seriously faced. The following protocols have been fully validated into Brazilian Portuguese at our Center: V-RQOL, VHI and VAPP and others are on the process, VHI-10. It is important to highlight that the validation of a protocol into another language requires not only a simple translation but cultural and linguistic issues must be considered.

Many researches have been performed in Brazil using the previously cited protocols for outcome measures and quality of life, with varied populations, such as normal and dysphonic individuals, head and neck cancer, voice professional users, and so on. We would like to provide a summary of each of them to show the panorama developed on the issue.

The largest study carried out in the country analyzed a large population of 2,214 individuals, 1304 with vocal complaint and 910 without vocal complaint that answered the Brazilian Version of the V-RQOL and a vocal self-assessment. The results indicated that the worse the self-assessment of voice, the lower the V-RQOL scores for both groups. However this relationship was more evident for the group with voice disorder¹⁰. Other important study focused on the difference of sexes. 1,316 individuals with diagnosis of voice disorder, 1,004 female and 312 male also answered the Brazilian V-RQOL and a voice self-assessment. Men and women had different perception of the impact of their voice disorder on their lives. Women perceived more impact on the physical domain, specially related to use of voice at work. They also had worse rating for vocal quality¹¹.

Another study also using the Brazilian V-RQOL analyzed the impact of a voice disorder due to head and neck cancer on the quality of life. The population consisted of 20 male individuals submitted to total laryngectomy, 10 using esophageal speech and 10 using tracheo-esophageal speech as means of communication. Results indicated that the organic voice disorder influenced more the aspects related to the physical domain and the tracheo-esophageal speakers had even worse scores¹².

Other study investigated the similarities and differences of call center attendants' perception by means of two quality of life measures: VHI and V-RQOL. 204 individuals, 159 female and 45 male, active and receptive attendants participated in the experiment. The individuals presented good voice-related quality of life. The active modality may present complaints related to the physical and organic domains. Both instruments provided similar results¹³.

Teachers had also been the focus of some voice-related quality of life research. One of them evaluated teachers with vocal complaint by means of a generic instrument, the SF-36 and of a specific instrument, the V-RQOL. 41 female teachers from public schools, aged between 26 to 56 years answered the two measures. The protocols indicated different level of deviation, given that the physical aspects presented lower scores (SF-36: 64,96; V-RQOL: 53,86). Moreover, quite interesting was the fact that the pain domain was deviated at the SF-36, a dimension that is not present in any voice protocol and requires a deeper comprehension¹⁴. Other experiment investigated the effects of a voice rehabilitation program on patients' voice and quality of life by means of the VAPP protocol. 23 patients with mean age of 20 years were submitted to 10 sessions of voice therapy and had their voice and the impact of their vocal problem evaluated pre and post-treatment. Results indicated that both the voice deviation and the impact of the voice problem on daily activities reduced after therapy. Specifically the daily communication item was the one that changed most¹⁵.

The conception and the validation of instruments that assess voice-related quality of life and similar protocols as the primary stages of an extensive process are indispensable to establish quality of life measures as a fundamental part of the dysphonic patient evaluation.

Cultural aspects should be seriously taken into account when validating a protocol but quality of life is an unquestionable worldwide demand.

REFERENCES

1. World Health Organization. Measuring Quality of Life – The World Health Organization Quality of Life Instruments. WHO/MSA/MNH/PSF. 1997;1-15.
2. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Ann Intern Med.* 1993;118:622-29.
3. Gill TM, Feinstein AR. A Critical Appraisal of the quality of Quality-of-life Measurements. *JAMA.* 1994;272(8):619-26.
4. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol.* 1993;46(12):1417-32.
5. Ciconelli RM, Ferraz MB, Santos W, Meinão I, Quaresma MR. Tradução para a língua portuguesa do questionário genérico de qualidade de vida SF-36 (Brasil SF-36). *Ver Bras Reumatol.* 1999; 39(3):143-50.
6. Hartnick CJ. Validation of a Pediatric Voice Quality-of-life Instrument: The Pediatric Voice Outcome Survey. *Arch Otolaryngol Head Neck Sur.* 2002;128(8):919-22.
7. Scientific Advisory Committee of Medical Outcomes Trust. Assessing health status and quality of life instruments: Attributes and review criteria. *Qual Life Res.* 2002;11:193-205.
8. Hogikyan ND, Sethuraman G. Validation of an instrument to measure voice-related quality of life (V-RQOL). *J Voice.* 1999;13(4):557-69.
9. Hogikyan ND, Wodchis WP, Spak C, Kileny RK. Longitudinal effects of Botulinum Toxin injections on Voice-related quality of Life (V-RQOL) for patients with adductory spasmodic dysphonia. *J Voice.* 2001;15(4):576-86.
10. Behlau M, Gasparini G, Hogikyan ND. Quality of Life and Voice: Study of a Brazilian Population using the Voice-Related Quality of Life (V-RQOL) Measure. *Pholia Foniatr Logop,* 2007, in print.
11. Mateus, SS. O impacto de uma disfonia nas diferentes afirmativas dos domínios analisados pelo protocolo QVV de acordo com o gênero. São Paulo, 2003/Monograph. Centro de Estudos da Voz. Supervisor: Mara Behlau.
12. Combochi R. Qualidade de vida dos laringectomizados totais com voz esofágica e voz tráqueo-esofágica. São Paulo, 2002/Monograph. Centro de Estudos da Voz. Supervisor: Mara Behlau.
13. Maisonnave IGW. Mensuração do IDV e QVV em atendentes de *call center*: uma análise comparativa. São Paulo, 2004/Monograph. Centro de Estudos da Voz. Supervisor: Mara Behlau.
14. Santarosa J. Avaliação da qualidade de vida de professores com queixa vocal por meio dos questionários SF-36 E QVV. São Paulo, 2003/Monograph. Centro de Estudos da Voz. Supervisor: Mara Behlau.
15. Ferraz P. Auto-avaliação do impacto vocal nas atividades de vida diária de professores por meio do protocolo PPAV. São Paulo, 2007/Monograph. Centro de Estudos da Voz. Supervisor: Mara Behlau.