

Transcultural adaptation of the Self-Evaluation of Communication Experiences After Laryngectomy (SECEL) instrument into Brazilian Portuguese

Adaptação transcultural do *Self-Evaluation of Communication Experiences after Laryngectomy (SECEL)* para o Português Brasileiro

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ABSTRACT

Purpose: To cross-culturally adapt the Self-Evaluation of Communication Experiences after Laryngectomy questionnaire into Brazilian Portuguese and to apply the first version of adaptation to patients. **Methods:** Initially, SECEL was independently translated from English into Brazilian Portuguese by a health professional and by an English teacher experienced in translation. Both translations were similar and used similar words and expressions. Later, these two translations were analyzed and a new translation was compiled by the researchers based on the previous two. It was back-translated – also independently – into English by a health professional and a Brazilian Portuguese speaker with English as his/her native language. These back-translations were combined into a single template by the researchers and sent to the author who developed the original questionnaire. After the author's approval, the questionnaire was applied to 39 patients who underwent total laryngectomy with at least one year after surgery. **Results:** The first block of the questionnaire – General Scale – was proved less suitable; the second – Environmental Scale – achieved high correction; the third – Attitudinal Scale – showed the highest correlation. **Conclusion:** This study achieved the first step of the validation of the questionnaire into Brazilian Portuguese – translation, cultural adaptation and preliminary analysis of the results, identifying failing questions. The new proposal after application of SECEL is presented to be used in a representative Brazilian population.

Keywords: Laryngectomy; Quality of life; Translating; Communication; Surveys and questionnaires

RESUMO

Objetivo: Adaptar transculturalmente o questionário *Self-Evaluation of Communication Experiences after Laryngectomy (SECEL)* para o português do Brasil e aplicar esta primeira versão da adaptação em pacientes. **Métodos:** Inicialmente, o instrumento foi traduzido do inglês para o português por um profissional de saúde e por um professor de inglês com experiência em tradução, de forma independente. Ambas as traduções foram semelhantes e usaram palavras e expressões similares. Posteriormente, nova versão foi criada, a partir da compilação das anteriores, e reconvertida para o inglês por um profissional de saúde e um falante do português, que tinha o inglês como língua nativa, também de forma independente. As retrotraduções foram reunidas em um documento único, que foi enviado para o autor que desenvolveu o questionário original. Após a aprovação do autor, o questionário foi aplicado em 39 pacientes submetidos à laringectomia total, com, pelo menos, um ano de pós-operatório. **Resultados:** O primeiro bloco do questionário – Questões Gerais – revelou-se menos adequado; o segundo bloco de questões – Aspectos Ambientais – apresentou alta correção e o terceiro – Questões Atitudinais – apresentou a maior correlação. **Conclusão:** O primeiro passo da validação do questionário em português – tradução, adaptação cultural e análise preliminar dos resultados, identificando falhas nas perguntas – foi realizado. A nova proposta, após o pré-teste do instrumento, foi apresentada para aplicação em uma população representativa do Brasil.

Descritores: Laringectomia; Qualidade de vida; Tradução; Comunicação; Inquéritos e questionários

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INTRODUCTION

Laryngeal cancer represents a large part of head and neck cancers⁽¹⁾. Its treatment often involves laryngectomy, for it provides better prognosis⁽²⁾, which results in permanent deprivation of laryngeal speech. Still, there is a gap in the studies regarding the quality of life of these patients, because the instruments most commonly used in this type of survey lack sensitive questions for communication, the most changed aspect of life for this particular type of cancer. Thus, there is no uniformity in studies evaluating the quality of life of patients, which makes it impossible to compare them^(3,4).

The loss of the ability to speak is one of the major damages caused by laryngectomy. As speech is the main form of communication for most people, losing it has a significant impact on their lives. There are treatments that help regain the ability to speak, but the process of adapting to the new reality can be slow and arduous. For this reason, the loss of speech is an important issue when considering the quality of life of patients undergoing laryngectomy. This aspect, however, as previously said, is not given the proper emphasis in cancer questionnaires⁽⁵⁾. The *Self-Evaluation of Communication Experiences after Laryngectomy* (SECEL) questionnaire was created to meet this need. Developed and published in 1993, it contains 35 specific questions about post-laryngectomy communication experiences⁽⁶⁾, as showed in Appendix 1.

Since the number of cases has been progressively increasing, mainly among females^(7,8,9), it is necessary to expand and improve the instruments that can help professionals in their choice of treatment and provide subsidies to understand implications of the treatment on patients' lives and to evaluate their progress and adapt to the new reality.

This study aimed at carrying out the translation and cultural adaptation of SECEL questionnaire into Brazilian Portuguese. This is the first stage of the instrument construction process, which presents the results obtained in the pretest of the translated and adapted instrument. In the second stage, the questionnaire will be validated in order to provide researchers and health professionals who treat these patients with a better tool for identifying issues related to quality of life, especially in relation to communication, facilitating decision-making for treatment and rehabilitation.

METHODS

The methods recommended in the literature and usually applied in studies of this type^(10,11,12,13) were used. The questionnaire was independently translated from English into Brazilian Portuguese by a health professional and by an English teacher experienced in translation. Both translations were similar and similar words and expressions were chosen. Later, a new version was created from the compilation of those translations and back-translated into English – also independently – by a

health professional and a Brazilian Portuguese speaker with English as his/her native language. The back-translations were combined into a single document, which was sent to the author of the original questionnaire. The process of translation, back-translation and submission to the original author for approval of the version took place in the second half of 2013.

After approval by the author of the original to the back-translated version of the questionnaire, the translated version was applied to patients who underwent total laryngectomy, between January 2000 and November 2013, at an university referral hospital in southern Brazil. Patients were contacted using the telephone numbers provided by them at the time of hospitalization for surgery, which are registered in the hospital database. The purpose and the procedures of the study were informed to the patients and their voluntary participation was requested by signing the Informed Consent Form and filling in the questionnaire translated into Brazilian Portuguese. To participate in the study, patients had to have at least one year post-laryngectomy.

Patients who agreed to participate in the study were informed about the option of receiving the visit of the researcher to complete the questionnaire or have it sent by mail or email. As the tool is a self-assessment and the instructions are in the header, the presence of the researcher not was necessary for the completion process. Along with the questionnaire, the Informed Consent Form was also provided, with guidance to be signed after reading, along with the completed questionnaire, and then returned. There was no interference by the researcher in the instrument filling in procedure nor did the patients get explanations beyond those in the header.

Out of a list with 166 patients, 85 (51.5%) died before the investigation. Out of the 81 (48.79%) remaining patients, 28 (24.13%) could not be located. Of the remaining patients, six (5.16%) chose to reply to the questionnaire sent by mail or e-mail, but did not return it completed; three (2.58%) refused to participate and five (4.31%) had other reasons for not participating. Thus, the sample consisted of 39 patients who completed the questionnaire.

The analysis of the questionnaires was carried out in two stages: the first one is a qualitative analysis of the answers provided by patients in the last page of the questionnaire, where there was a space to explain in their own words the reason for not understanding a question or the lack of clarity in one or in more of the questions of the instrument. The second one is a statistical analysis of the responses, using Cronbach's alpha to assess the reliability of the instrument. This test generates a score from 0 to 1, where values close to 0 correspond to low reliability and close to 1 correspond to high reliability.

This study followed the Resolution No. 466/2012 of the National Health Council for research on human subjects and was approved by the Ethics Committee of the *Universidade Federal do Rio Grande do Sul* under No. 414,519 / 13 and by

the Ethics Committee of the *Hospital de Clínicas de Porto Alegre* under No. 503,816 / 13.

All participants signed an Informed Consent Form.

RESULTS

In general, patients had no complaints regarding the instrument. Doubts were described in the last page of the questionnaire, placed there in order to make space so the patients could indicate their questions, misunderstandings or uncertainties.

Most of the study participants were men (82.1%), married (64.1%), with Elementary as maximum level of education (64.1%) and with no recovery of the speech skills (48.7%). The general characteristics of participants are shown on Chart 1.

Chart 1. Profile of survey participants

Item	Frequency (%)
Sex	
Male	32 (82.1)
Female	7 (17.9)
Education	
Elementary Education (or less)	25 (64.1)
Unfinished High School	3 (7.7)
Finished High School	7 (17.9)
Technical Course	1 (2.6)
University	3 (7.7)
Marital status	
Married	25 (64.1)
Divorced	3 (7.7)
Separated	3 (7.7)
Single	2 (5.1)
Widowed	6 (15.4)
Means of communication	
No talking	19 (48.7)
Esophageal speech	10 (25.6)
Electrolarynx speech	10 (25.6)

The profile questions were analyzed and there were some intelligibility issues such as: lack of the option “no voice / does not speak” as response alternatives to the question “main means of communication” – since in the United States, country of origin of the questionnaire, patients usually receive surgical treatment and/or speech therapy and eventually regain speech after laryngectomy; insecurity in pointing out some of the alternatives on the question “Marital Status”, since couples living together are often not legally married; inclusion of the group “Elementary Education (finished or not)” is required – when it comes to education – so that it is possible to examine the difference of adaptation to the new reality among patients who received no formal education,

who finished school to grade 5 (currently 6th year) and those who finished Elementary Education. An effort was made to try and solve these obstacles in the new version of the questionnaire.

The quality of life and communication questions that needed adjustments were identified by patients in the last page of the instrument and confirmed by Cronbach correlation analysis (Chart 2).

The reliability analysis of the questionnaire showed that it was difficult to understand some of the questions. The most recurrent problem was the use of the word “speak” referring to communication (questions 3, 5, 6, 7, 11, 12, 13 and 14). Another difficult point was found in questions 9 and 34, to which a positive response was required – but it was understood by patients as negative.

The questions using the term “speak” after laryngectomy were the ones revealing more inconsistencies between respondents. Since a large number of patients in the sample did not develop oral communication after the removal of the larynx, these questions were misunderstood: they did not know whether they should answer or ignore them.

Negative questions that required a positive response, but the perception of patients was negative, also had a significant occurrence of inconsistencies, quite possibly demonstrating that positive responses did not properly reflect the perceptions of patients about their health.

DISCUSSION

Based on the findings of the first back-translated version of the instrument, we present a new proposal for the organization of sentences, as outlined in the right column (New Question Proposal) in Chart 2. The questions with low correlation in the Cronbach test and that were criticized by the patients who completed the questionnaire were reviewed and changed.

The pre-test results showed that the mortality rate in this population is even higher than the most pessimistic data presented in the previously published studies⁽⁸⁾, which requires a larger sample for future studies. Estimates consistent with the findings of this study should be considered, such as higher mortality for the period of ten years than reported in other studies; predominance of no restoration of the speech ability after laryngectomy; low educational level of patients.

With this sample it was possible to satisfactorily perform the pre-test and suggest improvements necessary for the instrument validation into Brazilian Portuguese (Appendix 2).

CONCLUSION

The pretest provided realistic data aimed at the Brazilian situation with regard to the mortality due laryngectomy, which will provide more accuracy in the sample size calculations required for the instrument validation study.

Chart 2. Adjustments in the questions after the results of the pretest

	Original question	Correlation with the instrument*	Difficulty in understanding by patients (absolute frequency)	New question presented
1	Você se sente tranquilo e confortável junto a outras pessoas em situações de diálogo?	0.425	-	-
2	Você se descreveria como uma pessoa calma, comedida?	-0.018	1	Você se descreveria como uma pessoa tranquila, reservada?
3	Você é uma pessoa ativa, extrovertida, falante?	0.092	1	Você é uma pessoa ativa, extrovertida, comunicativa?
4	Você admite à pessoa com quem conversa que realizou uma laringectomia?	0.185	1	Você fala para a pessoa com quem conversa que realizou uma laringectomia?
5	Você acha que sua fala melhora com o tempo que você a usa?	0.009	2	Você acha que a sua comunicação melhora com o tempo?
6	Você diria que vai menos a clubes, encontros e outros eventos sociais por causa de sua fala?	0.096	-	Você deixa de ir a clubes, encontros e outros eventos sociais por causa da sua comunicação?
7	Você tem dificuldade em chamar a atenção das pessoas para falar?	0.385	1	Você tem dificuldade em chamar a atenção das pessoas para se comunicar?
8	Você tem dificuldade em gritar ou chamar pessoas?	0.602	2	Você tem dificuldade em gritar?
9	Você acha que as pessoas não conseguem lhe entender?	0.278	-	Você acha que as pessoas tem dificuldade de lhe entender?
10	Você acha que tem de repetir as coisas durante uma conversa para ser entendido?	0.628	-	-
	Você tem dificuldade falando:			Você tem dificuldade de se comunicar:
11	Em grandes grupos?	0.713	1	Com um grande grupo?
12	Em pequenos grupos?	0.628	1	Com um pequeno grupo?
13	Com uma pessoa apenas?	0.510	1	-
14	Em diferentes cômodos de sua casa (apartamento, residência)	0.277	1	A uma certa distância da outra pessoa?
15	Em locais barulhentos?	0.423	-	-
16	Ao telefone?	0.565	-	-
17	No carro, ônibus, ou viajando?	0.582	-	-
	A sua fala lhe faz:			Após a cirurgia você passou a:
18	Ter dificuldades em ir a festas ou encontros sociais?	0.465	-	-
19	Usar o telefone menos do que gostaria?	0.528	-	-
20	Se sentir deixado de lado em um grupo?	0.463	-	-
21	Limitar sua vida social ou pessoal?	0.637	1	-
	A sua fala faz você se sentir:			-
22	Triste, deprimido?	0.603	-	-
23	Frustrado ao não ser compreendido por parentes e amigos?	0.675	-	-
24	Diferente ou estranho?	0.639	1	Diferente dos outros ou estranho?
25	Você evita conhecer novas pessoas por causa de sua fala?	0.709	-	-

Chart 2. Adjustments in the questions after the results of the pretest (cont.)

	Original question	Correlation with the instrument*	Difficulty in understanding by patients (absolute frequency)	New question presented
26	Você fica “de fora” de conversas por causa de sua fala?	0.579	-	-
27	Você evita falar com outras pessoas por causa de sua fala?	0.574	-	-
28	As pessoas tendem a completar palavras ou frases para você?	0.408	-	-
29	As pessoas lhe interrompem enquanto você fala?	0.482	-	-
30	As pessoas falam que não entendem você?	0.546	-	-
31	As pessoas com quem você fala ficam incomodadas com sua fala?	0.743	2	Você acha que as pessoas ficam incomodadas com a forma como você se comunica?
32	As pessoas lhe evitam por causa de sua fala?	0.601	-	-
33	As pessoas falam com você de forma diferente por causa de sua fala?	0.509	-	-
34	Seus familiares e amigos não entendem como é se comunicar da sua forma?	0.137	1	Seus familiares e amigos têm dificuldade de compreender as suas limitações de comunicação?

*Cronbach's alpha test

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Appendix 1. Questionnaire original SECEL in English

Self-Evaluation of Communication Experiences After Laryngectomy (SECEL)*

Personal information

Name _____ Date of Birth ___/___/_____
 Sex: Male ___ Female ___ Race _____

Primary means of communication

Esophageal speech ___ Tracheo-esophageal speech ___
 Artificial larynx speech ___ Other ___

Education completed

Elementary school or less ___ Some high school ___ High school graduate ___
 Some college ___ College graduate ___ Graduate school or more ___

Are you current employed

Part-time ___ Full time ___ Self-employed ___ Not employed ___ Retired ___
 Unpaid employment (volunteer work) ___

What was (is) your occupation? _____

Marital status and whether this is the first, second, etc. marriage

Single ___ Married ___ (how long?) ___ Divorced ___ (how long?) ___
 Separated ___ (how long?) ___ Widowed ___ (how long?) ___

Date of cancer diagnosis? _____

What type of surgery did you have?

Total laryngectomy ___ Partial laryngectomy ___, what was removed? _____
 Radical neck dissection ___, left ___ or right ___ or both ___?
 Other _____

Instructions

Here are 35 statements about experiences with communication after a laryngectomy. These experiences have been reported by laryngectomees. Read each of the statements carefully and please draw a CIRCLE around the number that describes you NOW or in the last 30 days. It does not mean the last year or things that happened many years ago. The following example shows you how.

	Always	Often	Sometimes	Never
1. Do you have trouble speaking to family and friends?	3	2	①	0
2. Do you feel that people interrupt you because of your speech?	3	②	1	0

	Always	Often	Sometimes	Never
1. Are you relaxed and comfortable around other people in speaking situations?	3	2	1	0
2. Would you describe yourself as a low-keyed, calm person?	3	2	1	0
3. Are you an active, "outgoing", talkative person?	3	2	1	0
4. Do you admit to the person you are speaking to that you had a laryngectomy?	3	2	1	0
5. Do you think your speech improves with the amount of time you use it?	3	2	1	0
6. Do you find that you frequent clubs, meetings, or lodges less often because of your speech?	3	2	1	0
7. Do you have difficulty having getting people's attention to speak?	3	2	1	0
8. Do you have difficulty yelling or calling out to people?	3	2	1	0
9. Do you find that people are unable to understand you?	3	2	1	0
10. Do you find you have to repeat things a number of times during conversations to be understood?	3	2	1	0
Do you have trouble with speaking:	3	2	1	0
11. In large groups of people?	3	2	1	0
12. In small groups of people?	3	2	1	0
13. With one person?	3	2	1	0
14. In different rooms of your house (apartment, residence)	3	2	1	0
15. In loud or noisy places?	3	2	1	0
16. On the telephone?	3	2	1	0
17. In the car, bus or while traveling?	3	2	1	0
Does your speech cause you to:				
18. Have difficulty when attending parties or social gatherings?	3	2	1	0
19. Use the telephone less often than you would like?	3	2	1	0
20. Feel left out when you are with a group of people?	3	2	1	0
21. Limit your social life or personal life?	3	2	1	0
Does your speech cause you to feel:				
22. Depressed?	3	2	1	0
23. Frustrated when talking to family and friends and they can't understand you?	3	2	1	0
24. Different or peculiar?	3	2	1	0
25. Do you hesitate to meet new people because of your speech?	3	2	1	0
26. Do you get left out of conversations because of your speech?	3	2	1	0
27. Do you avoid speaking with other people because of your speech?	3	2	1	0
28. Do people tend to fill in words or complete sentences for you?	3	2	1	0
29. Do people interrupt you while you are speaking?	3	2	1	0
30. Do people tell you that they can't understand you?	3	2	1	0
31. Do the people you speak with get annoyed with you because of your speech?	3	2	1	0
32. Do people avoid you because of your speech?	3	2	1	0
33. Do people speak to you differently because of your speech?	3	2	1	0
34. Do your family and friends fail to understand what it's like to communicate with this type of speech?	3	2	1	0
35. Do you talk the same amount now as before your laryngectomy?	Yes	More	Less	

*Questionnaire developed by Gordon Blood. Available at: Blood G. Development and assessment of a scale addressing communication needs of patients with laryngectomies. *Am J Speech Lang Pathol.* 1993;2(3):82-90. <http://dx.doi.org/10.1044/1058-0360.0203.82>

Appendix 2. Questionnaire SECEL adapted to Brazilian Portuguese

Questionário de Autoavaliação das Experiências Comunicativas Pós-Laringectomia (AECOP)

Informações pessoais

Nome _____ Data de Nascimento ___/___/_____

Sexo: Masculino ___ Feminino ___ Cor/Raça _____

Principal meio de comunicação

Fala esofágica ___

Ausência de voz/ não fala/ fala sussurrada ___

Fala com aparelho eletrolaríngeo ___

Outro ___ Qual? _____

Escolaridade

Analfabeto ___ Até a 5ª série ___ Até a 8ª série ___

Ensino médio incompleto ___ Ensino médio completo ___

Ensino superior incompleto ___ Ensino superior completo ___

Está empregado no momento?

Meio período ___ Período integral ___

Autônomo ___ Não empregado ___ Aposentado ___

Trabalho não remunerado (voluntário) ___

Qual é sua ocupação? _____

Qual era sua ocupação antes da cirurgia? _____

Estado civil, e há quanto tempo na presente situação:

Solteiro ___ Casado / morando junto ___ Divorciado ___

Separado ___ Viúvo ___ Há quanto tempo? ___

Ano do câncer diagnosticado _____

Ano da cirurgia _____

Por que tipo de operação você passou?

Laringectomia total ___ Laringectomia parcial ___, o que foi removido? _____

Dissecação radical de pescoço ___, esquerda ___ ou direita ___ ou ambos ___?

Outro _____

Instruções

Abaixo, seguem 35 proposições sobre experiências em comunicação após uma laringectomia. Estas experiências foram descritas por laringectomizados. Leia cada proposição com atenção e desenhe um CÍRCULO ao redor do número que lhe descreve NO MOMENTO, ou nos últimos 30 dias. Não se aplica o ano anterior ou coisas que lhe ocorreram há vários anos. O exemplo mostra como proceder.

	Sempre	Frequentemente	Às vezes	Nunca
1. Você tem dificuldades ao falar com familiares ou amigos?	3	2	1	0
2. Você acha que as pessoas lhe interrompem por causa de sua fala?	3	2	1	0

	Sempre	Frequentemente	Às vezes	Nunca
1. Você se sente tranquilo e confortável junto a outras pessoas em situações de diálogo?	3	2	1	0
2. Você se descreveria como uma pessoa tranquila, reservada?	3	2	1	0
3. Você é uma pessoa ativa, extrovertida, comunicativa?	3	2	1	0
4. Você fala para a pessoa com quem conversa que realizou uma laringectomia?	3	2	1	0
5. Você acha que a sua comunicação melhora com o tempo?	3	2	1	0
6. Você deixa de ir a clubes, encontros e outros eventos sociais por causa da sua comunicação?	3	2	1	0
7. Você tem dificuldade em chamar a atenção das pessoas para se comunicar?	3	2	1	0
8. Você tem dificuldade de gritar?	3	2	1	0
9. Você acha que as pessoas tem dificuldade de lhe entender?	3	2	1	0
10. Você acha que tem de repetir as coisas durante uma conversa para ser entendido?	3	2	1	0
Você tem dificuldade de se comunicar:				
11. Com um grande grupo?	3	2	1	0
12. Com um pequeno grupo?	3	2	1	0
13. Com uma pessoa apenas?	3	2	1	0
14. A uma certa distância da outra pessoa?	3	2	1	0
15. Em locais barulhentos?	3	2	1	0
16. Ao telefone?	3	2	1	0
17. No carro, ônibus, ou viajando?	3	2	1	0
Após a cirurgia você passou a:				
18. Ter dificuldade para ir a festas ou encontros sociais?	3	2	1	0
19. Usar o telefone menos do que gostaria?	3	2	1	0
20. Se sentir deixado de lado em um grupo?	3	2	1	0
21. Limitar sua vida social ou pessoal?	3	2	1	0
A sua fala faz você se sentir:				
22. Triste, deprimido?	3	2	1	0
23. Frustrado ao não ser compreendido por parentes e amigos?	3	2	1	0
24. Diferente dos outros ou estranho?	3	2	1	0
25. Você evita conhecer novas pessoas por causa de sua fala?	3	2	1	0
26. Você fica “de fora” de conversas por causa de sua fala?	3	2	1	0
27. Você evita falar com outras pessoas por causa de sua fala?	3	2	1	0
28. As pessoas tendem a completar palavras ou frases para você?	3	2	1	0
29. As pessoas lhe interrompem enquanto você fala?	3	2	1	0
30. As pessoas falam que não entendem você?	3	2	1	0
31. Você acha que as pessoas ficam incomodadas com a forma como você se comunica?	3	2	1	0
32. As pessoas lhe evitam por causa de sua fala?	3	2	1	0
33. As pessoas falam com você de forma diferente por causa de sua fala?	3	2	1	0
34. Seus familiares e amigos tem dificuldade de compreender as suas limitações de comunicação?	3	2	1	0
35. Comparado a antes da laringectomia, você fala mais ou menos agora?	O mesmo	Mais	Menos	