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# Instruments in Brazilian Sign Language for assessing the quality of life of the deaf population

## ABSTRACT

**OBJECTIVE:** To construct versions of the WHOQOL-BREF and WHOQOL-DIS instruments in Brazilian sign language to evaluate the Brazilian deaf population's quality of life.

**METHODS:** The methodology proposed by the World Health Organization (WHOQOL-BREF and WHOQOL-DIS) was used to construct instruments adapted to the deaf community using Brazilian Sign Language (Libras). The research for constructing the instrument took place in 13 phases: 1) creating the QUALITY OF LIFE sign; 2) developing the answer scales in Libras; 3) translation by a bilingual group; 4) synthesized version; 5) first back translation; 6) production of the version in Libras to be provided to the focal groups; 7) carrying out the Focal Groups; 8) review by a monolingual group; 9) revision by the bilingual group; 10) semantic/syntactic analysis and second back translation; 11) re-evaluation of the back translation by the bilingual group; 12) recording the version into the software; 13) developing the WHOQOL-BREF and WHOQOL-DIS software in Libras.

**RESULTS:** Characteristics peculiar to the culture of the deaf population indicated the necessity of adapting the application methodology of focal groups composed of deaf people. The writing conventions of sign languages have not yet been consolidated, leading to difficulties in graphically registering the translation phases. Linguistics structures that caused major problems in translation were those that included idiomatic Portuguese expressions, for many of which there are no equivalent concepts between Portuguese and Libras. In the end, it was possible to create WHOQOL-BREF and WHOQOL-DIS software in Libras.

**CONCLUSIONS:** The WHOQOL-BREF and the WHOQOL-DIS in Libras will allow the deaf to express themselves about their quality of life in an autonomous way, making it possible to investigate these issues more accurately.

**DESCRIPTORS:** Hearing Loss. Quality of Life. World Health Organization. Questionnaires. Translations. Sign Language. Validity of Tests. Reproducibility of Results. Health of the Disabled.

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## INTRODUCTION

One of the challenges facing XXI century society is to interact, respecting diversity and ensuring equal rights. This includes interacting with people with disabilities. In the case of those with impaired hearing, this also implies the recognition of sign language and the culture of the deaf population.

Before becoming official, sign language was known by various terms: language of gestures, language of the deaf, gestures, mime, acting or hand movements were all used to refer to the way the deaf communicated amongst themselves. These terms were influenced and reinforced by the oralist concept which maintained that the deaf should speak, become oralized at any cost and the use of signing prohibited.

The social relationships afforded by the deaf community enabled the deaf to create their own identity in the world. This justifies the results of research which show better quality of life in the dominion of social and emotional relationships in the deaf who were participants in their community.<sup>4,5</sup> Good coexistence with the deaf implies experiencing deaf culture, recognition of sign language and of the deaf community.<sup>3</sup>

This new concept legitimized cultural aspects of the deaf population and sign language is that which most stands out among this population's cultural traits. In addition to being a linguistic system, it is an integral element of the deaf subject, adding to their identity and culture. The right to communicate in their natural language, i.e., in Brazilian Sign Language (Libras), is legally guaranteed in Brazil, without the imposition to speak the country's main language.

Lack of recognition of this linguistic peculiarity makes it difficult for the deaf to access primary health care services offered by the public health system, the Brazilian Unified Health System (SUS). A lack of interpreters and of training on the part of the employees dealing with the deaf are aspects which weaken the communicative link in carrying out appropriate treatment.<sup>3,10</sup> It is imperative that health care professionals know the issues involved in the deaf culture and identity, so as not to compromise the care with which they are provided.<sup>3</sup>

The tools for measuring Quality of Life Related to Health have been translated and validated in various languages with the aim of incorporating the socio-cultural and linguistic values of a population.<sup>11</sup> Why should these same criteria not be considered in relation to the deaf population? How could a reliable assessment of the quality of life of the deaf who use sign language be achieved using instruments in a language of which

they do not have mastery? Would it be more prudent to use a version of the questionnaire in Portuguese, with a simultaneous translation into sign language? Bearing in mind that Libras is a legally recognized language, Federal Law n° 10.436/02,<sup>a</sup> would it not be necessary to translate and validate instruments for measuring quality of life into this language?

The World Health Organization instruments for measuring quality of life (WHOQOL) are available in more than 20 languages,<sup>2,6</sup> but there are no studies which translate and validate these instruments into Libras. Few researchers have investigated the quality of life of the deaf population who communicate in sign language. The majority of these studies aimed to investigate quality of life with regards the use of a hearing aid or cochlear implant, from the perspective of valorizing oral language.

The WHOQOL Group proposed that their instruments for assessing quality of life be translated into various languages and that they possessed good levels of equivalence so that the results reliably reflected the quality of life of a specific community in their transcultural use.<sup>2,7</sup> It is, therefore, imperative that the World Health Organization Quality of Life – Bref (WHOQOL-BREF) and World Health Organization Quality of Life – Disability (WHOQOL-DIS) be translated into sign language, in this case, into Libras.

This study aimed to construct a version of the WHOQOL-BREF and WHOQOL-DIS instruments in Brazilian Sign Language in order to evaluate the quality of life of the Brazilian deaf population.

## METHODS AND RESULTS

### Developing a version of the WHOQOL-BREF and WHOQOL-DIS in Libras

The development of the Libras version of the WHO instruments for measuring quality of life, WHOQOL-BREF and WHOQOL-DIS, formed part of the WHOQOL-Libras project.

### Stages

The methodology used followed the criteria established by the WHO and consisted of 13 stages:

#### 1) Creating the “Quality of Life” sign

In Libras there was no sign for the term ‘quality of life’. Therefore, a study of this concept in the deaf

<sup>a</sup>Brasil. Decreto n° 5.626, de 22 de dezembro de 2005. Regulamenta a Lei n° 10.436, de 24 de abril de 2002, que dispõe sobre a Língua Brasileira de Sinais – LIBRAS e o art. 18 da Lei n° 10.098, de 19 de dezembro de 2000. *Diário Oficial União*. 23 dez 2005:28.

community was necessary. After much discussion and the presentation of different proposals for the sign, a group of deaf individuals voted on a sign for quality of life.

The sign for 'quality of life' is made on the left side of the thorax, near the heart. The morphological classification of the sign consists of joining two simple signs to form a composite, as in the example: *marvelous* + *life* = *quality of life*.

When creating a sign for quality of life for the deaf, a change was made to the place in which the sign for 'marvelous' was made, to include a subjective aspect to the term 'quality of life': this sign is normally made in the neutral area, i.e., in front of the thorax, without any contact with the body. In this new context, forming part of the sign for *quality of life*, it was moved to the left side of the thorax, near the heart, and touching the body. This phonological alteration characterizes the subjective aspect of the construct quality of life.

## 2) Response Scales in Libras

This stage was carried out based on the methodology of developing response scales in Portuguese, with adaptations appropriate to Libras, with the participation of 21 deaf individuals.

Responses to the WHOQOL questions are given on a Likert-style scale. Each scale has five possible answers. The words (responses) localized at the extremes of each scale were easily translated into the different oral languages.<sup>2</sup> However, when the responses were translated into Libras, various terms with the same semantic equivalence were found, even at the ends of each scale.

In order to carry out the survey of signs capable of including the values of the scale in terms of "Frequency, Intensity, Capacity, Evaluation", research was carried out in the deaf community, in lexicographical works, handouts from different Libras courses and in signs used by the bilingual group. There were 46 signs which were selected.

A visual-analogue scale was created with 100 mm per sign, in which the deaf individuals had to mark on the ruler the value attributed to that sign.

## 3) Translation by the Bilingual Group

The bilingual group which did the first translation of the WHOQOL-BREF and WHOQOL-DIS questionnaires from Portuguese into Libras was composed of four people without hearing impairment, children of deaf parents, fluent in Libras. Linguistic studies state that the first language (L1) of children of deaf parents who themselves do not have hearing impairment is usually sign language.<sup>10</sup> Therefore, it was decided to form this group from children of deaf parents who did not suffer

hearing impairment. Moreover, they had to work, or have worked, as interpreters.

## 4) Synthesized version

The translations of the questionnaires by the bilingual group were analyzed by the coordinators of the WHOQOL-Libras Project, fluent in Libras.

The procedure was the following:

a) the work of all the members of the group, on different computers, was monitored, facilitating the process of analysis;

b) discussion of how each produced (signed) the question was discussed in order to create the version which best represented the bilingual group's translation;

c) the synthesized version of each question was filmed.

No significant differences were detected between the translations carried out by the members of the bilingual group during the analysis of the questions. A synthesized version in Libras of the WHOQOL-BREF and WHOQOL-DIS questionnaires, recorded on a Digital Versatile Disk (DVD) was obtained.

## 5) First Back-translation

The aim of this stage was to re-translate the Libras version of the WHOQOL-BREF and WHOQOL-DIS into Portuguese and to analyze the semantic equivalence between the languages. The interpreter watched the filming of the questionnaires in Libras and noted the translation into Portuguese. This was carried out by an interpreter who had not taken part in the WHOQOL-Libras Project team, as recommended by WHO methodology.

## 6) Conversion into Libras

A version in Libras was produced, based on the first back-translation, to be analyzed by the focus groups.

## 7) Focus groups

The aims of the focus groups were: to analyze the Libras version; to revise the linguistic structure of the Libras in the questions produced by the bilingual group; to evaluate understanding of the questions; to identify other aspects which had not been included and which were relevant to the Brazilian deaf community; to discuss the importance of each aspect.

The sample was selected for convenience due to the characteristic of the investigation in the focus groups. Three focus groups were created: a group of deaf individuals (nine members), a group of family members of deaf individuals (six people) and a group of Libras interpreters (six people).

The focus groups met twice. The first with the aim of explaining the “WHO Quality of Life” project and present the WHOQOL-Libras project. The aim of the second meeting was to collect focus group data.

The rules of objectivity were followed; speak to one person at a time, avoid parallel conversations and respect the opinions of the others in the family and interpreters groups. All of the questions were deemed to be important. Alterations were suggested for some signs and alterations in the syntax of some phrases. When asked if they felt anything was missing in order to evaluate the quality of life of deaf individuals the suggestions were: family communication, family interaction (relationship), sports, technology, cochlear implant, accessibility of information and news.

There was some difficulty with regards the rules of objectivity in the deaf group. All of the questions were deemed to be important. Some suggestions were made with regards to semantic, syntactical and pragmatic aspects of the Libras versions. Other topics were also suggested: acquiring sign language, sports, family relationships and cochlear implants. A DVD version was produced to be returned to the focus groups to present the result.

#### 8) Revision by a mono-lingual group

Libras was the first language (L1) of the deaf individuals who participated in this stage, and Portuguese their second language (L2). They did not have total mastery of Portuguese and, as with many deaf individuals, showed difficulties with auditory-verbal type languages.

Cases of individuals who are not exclusively monolingual, such as the deaf individuals who participated in this stage, are anticipated by the WHO in their translation methodology. In some regions, it is unlikely that individuals with no knowledge of the questionnaire’s original language will be found. In such situations, the monolingual group should observe the aspects of the translation which are incomprehensible or with ambiguous linguistic structures according to the target language.

The two deaf individuals who took part in this stage had no access to the Portuguese versions of the WHOQOL-BREF and WHOQOL-DIS. They were instructed to analyze the linguistic structure of the questions and observe whether the Libras signs were clear and understandable. They considered the questionnaires important in evaluating the quality of life of the deaf. They suggested rephrasing some syntax and substituting some signs which did not agree with the meaning of the sentence.

#### 9) Revision by the Bilingual Group

This stage aimed to analyze the results from the focus groups and by the monolingual group.

The bilingual group watched the Libras version and discussed understanding and appropriateness of the linguistic structure. Later, they compared it with the Portuguese version to verify the equivalence between the languages involved in the translation process.

The coordinators of the WHOQOL-Libras Project analyzed and discussed the proposals for alterations from the bilingual group, weighing the suggestions for each question. Some were incorporated into the Libras version, others were included in the software glossary and others discarded. At the end of the analysis, there was result for each question. The next step was to make the filming available for working on the second back translation.

#### 10) Syntactical-Semantic Analysis and second back-translation

The objectives of this stage were: to evaluate the syntactical and semantic structure of the questions; second back-translation of the Libras questionnaires into Portuguese.

The syntactical and semantic analytical process and that of the second back-translation may be described thus (Table 1):

- the interpreter was asked to watch the Libras video and translate it into Portuguese;
- the translation and the respective question in the Portuguese version were read;
- the semantic value of the question in the Portuguese version was discussed in order to verify the meaning of the question was included in the Libras version;
- when there was no semantic equivalence between the versions, the way to express the concept in Libras was discussed and the proposed alteration recorded.
- The discussion of each question at the linguistic, syntactical and semantic level, including the suggestions for alterations to some signs, are exemplified again:

##### Question 1:

- Change the sign INVESTIGATE (meaning to investigate/study) for EVALUATE.

Question 36: The sign for EXAMPLE is missing and the meaning of “hear you”

- Add the sign for EXAMPLE and the sentence PERCEIVE OTHERS ATTENTION (two hands on the face and the thorax).

**Table 1.** Second Back-translation and semantic evaluation of WHOQOL-BREF and WHOQOL-DIS

WHOQOL-BREF and WHOQOL-DIS in Portuguese	WHOQOL-BREF and WHOQOL-DIS in Libras	Back-translation into Portuguese	Semantic equivalence
2G. How satisfied are you with your health?	YOU SATISFIED YOUR HEALTH MEASURE HOW ?	How satisfied are you with your health?	Yes
10. Do you have enough energy for everyday life?	EFFORT DAY YOU CAN SUPPORT HOW?	You exert yourself excessively during the day?	Partial
33. Do you make the big decisions in your life? <i>For example, deciding where to live, or with whom to live, how you spend your money.</i>	IMPORTANT THINGS YOU CHOOSE YOUR LIFE HOW? EXAMPLE: YOU CHOOSE HOW PLACE HOUSE? YOU CHOOSE HOW YOU PEOPLE TOGETHER HOUSE? YOU CHOOSE SPEND (pocket) SPENDING (palm) HOW MONEY?	You decide (choose) about important issues in your life? For example: where to live, with whom you live, how you spend your money.	Yes
34. Are you satisfied (a) with your ability to communicate with others? <i>For example, how you say things or defend your point of view, how you understand other people, through words or signs.</i>	YOU SATISFIED YOUR SKILL (work) COMMUNICATION HOW? EXAMPLE: YOU SAY THINK CONSCIOUSNESS (with the forehead) OWN HOW? YOU UNDERSTAND HOW PEOPLE ORAL Libras? YOU SATISFIED YOUR COMMUNICATION HOW?	Are you satisfied with your communication skills? For example: you say what you think? How do you understand what you are oralizado or signed?	Partial

WHOQOL-BREF: World Health Organization Quality of Life-Bref

WHOQOL-DIS: World Health Organization Quality of Life – Disability

Libras: *Língua Brasileira de Sinais*

Even with good semantic equivalence between the questions in the back-translations, ungrammatical items were found in Libras, as the grammatical structure of this language is directly linked to its visuo-spatial means of production. The ungrammatical items found were: direction of gaze, inappropriate facial expression (exaggerated or inexpressive) missing the context and lack of fluidity in Libras in executing the signs.

11) Re-evaluation of the second back-translation by the bilingual group

The aim was to re-evaluate the second back-translation and make the last alterations to produce the final version of the WHOQOL-BREF and WHOQOL-DIS instruments.

The bilingual group watched the version produced based on the second back-translation and gave their opinions after the each question.

This version of the questionnaires presented a more precise and understandable linguistic structure and signing than the previous versions. Some small alterations to the alterations of the signs were necessary, such as the configuration of the hand, movement, use of space and facial expression, in order to obtain a production appropriate to the Libras linguistic structure.

12) Filming of the final version in a recording studio

The questions were produced by translators/deaf actors, fluent in Libras, signed in a clear manner with good facial expression. This could be compared to individuals without hearing impairment speaking clearly.

13) Developing the software in the Libras version of the WHOQOL-BREF and WHOQOL-DIS instruments

Software in Libras was developed to evaluate the quality of life of the Brazilian deaf population and to investigate the use of the software in the deaf community.

### Presenting the WHOQOL-Libras software

The software has the following access options:

#### A. WHOQOL/Libras – Quality of life

Presents the concept of quality of life proposed by the WHO, the creation of the QUALITY OF LIFE sign and an explanation of the translation carried out based on the Portuguese version. The Libras version appears under each text in Portuguese.

#### B. Instructions

Contains instructions on how to respond to the questions.

#### C. Application of the questionnaires

The researcher should apply to the WHOQOL-Libras coordinators for registration when the WHOQOL-BREF and WHOQOL-DIS questionnaires are to be used. After entering and sending their data as a “Registered interviewer”, a screen in which the questionnaire can be chosen will open.

Next, the interviewer will have access to the WHOQOL-BREF and WHOQOL-DIS questionnaires. WHOQOL-Libras presents the questionnaires in Libras, Portuguese, English and Written Sign Language – *Escrita das*

*Línguas de Sinais* (ELiS). The writing in Portuguese, English and in sign language were added to Libras (the main language of the software) to aid in understanding the questions.

The interview subject will have the opportunity to watch the same question as many times as they want to, to return to the previous question, to choose between the written languages (Portuguese, English and sign language) and, if necessary, use the Libras glossary.

The presentation of responses follows the same pattern as the questions, shown in Libras, and written in Portuguese, English and sign language.

In the software the following fields are also available: "Produce reports", "Demonstration", "Contact" and "Libras Glossary".

The WHOQOL-Libras Project was approved by the Ethics Committee for Human and Animal Medical Research of the *Hospital das Clínicas, Universidade Federal de Goiás* (Protocol nº 003/2008). All participants signed consent forms.

#### Usability of the WHOQOL-Libras software

The usability of the software was evaluated by 21 deaf individuals, students on a degree course in Literature/Libras at UFG and the Universidade Federal de Santa Catarina (UFSC) in the *Instituto Federal de Educação, Ciência e Tecnologia de Goiás* (IFG-GO). The criteria for selection of the sample of deaf individuals were: being a deaf Libras user and knowing how to use a computer.

A questionnaire was drawn up to assess the usability of the software including the following items: Personal information; Software interface; Software design; Linguistic aspects of Libras (Table 2).

The WHOQOL/Libras software developed in this study is property of the WHO and is available on the <http://www.medicina.ufg.br/qualidadedevida/> website and the WHOQOL website in Brazil: <http://www.ufrgs.br/psiq/whoqol.html>. Access is free to the scientific community.

## DISCUSSION

The quest to guarantee universal access to services marked the first 20 years of the SUS, which sought to guarantee health care, recognizing this to be the citizens' right and the State's duty. Constructing concepts and practices aimed at comprehensive care occurred at a slower pace.<sup>1</sup> However, the managers' experience showed the need to understand social determinants in order to prioritize communities health care needs.<sup>8</sup>

This fact strengthened the understanding that it is necessary to offer equal access and increase the degree

**Table 2.** Evaluation of WHOQOL-Libras software.

Items evaluated in the software	Positive evaluation (Very good/good)	%
Presentation	21	100.0
Clarity of instructions	16	76.2
Sufficient information to use the software	19	90.5
Ease of use	21	100.0
Design of the presentation	21	100.0
Color shirt worn by the individual signing the questions	21	100.0
Color shirt worn by the individual signing the responses	21	100.0
Background color used in the presentation	20	95.2
Esthetic	20	95.2
Clarity in the visualization of the signals	21	100.0
Rating of the size of the image dedicated to questions in Libras	21	100.0
Rating of the size of the image dedicated to responses in Libras	21	100.0
Adequacy of the spatial organization of the signs	21	100.0
Adequate fluency in Libras	19	95.0
Visual rating	21	100.0

WHOQOL-Libras: World Health Organization Quality of Life – *Língua Brasileira de Sinais*

of autonomy of subjects and communities in order to reduce public health care vulnerability and provide comprehensive health care.<sup>8</sup>

To measure the quality of life of the deaf, considering the characteristics of the deaf population, including cultural and linguistic aspects is indispensable. For those who communicate using sign language, quality of life can only be effectively assessed using instruments translated and adapted to this population.

Health care for those with disabilities used to be limited to preventing infectious diseases and rehabilitation undertaken by charitable and philanthropic institutions.<sup>9</sup> The creation of the SUS in 1988 meant that important strategies could be drawn up for primary care and social interaction practices developed, as well as transforming the position of disability. It is necessary to invest in technical and human training in order to promote communication between the health care network and the deaf population.<sup>3,10</sup>

The National Health Policy for People with Disabilities was established by the MS/GM Resolution nº 1,060 on 5<sup>th</sup> June 2002.<sup>b</sup> This policy included promoting quality

of life as a shared social responsibility, improving information mechanisms to stimulate research in health care and disabilities, qualifying records and collecting data and enabling the production and distribution of educational and informative material on health care in accessible formats in Braille and Libras.<sup>8</sup>

In order to promote care of the quality of life of this population it was necessary, in addition to qualifying human resources, to create instruments capable of measuring the quality of life of the deaf individual in relation to health care.

The methodology proposed by the WHO for constructing and validating instruments for evaluating quality of life is efficient. However, in order to guarantee accessibility and autonomy for the deaf to be able to express themselves about their quality of life, some adaptations were necessary. This confirms the importance of the content of Law n° 10,436/2002,<sup>a</sup> which recognizes Libras as the deaf community's official means of communication and expression.

In order to translate and adapt instruments into sign language the following items need to be observed:

1. the participation of individuals fluent in Libras in the team coordinating the project of translating oral language into sign language is indispensable;
2. creating a bilingual group to do the first translation from oral into sign language should follow certain criteria, ensuring that the members, in addition to being bilingual, have experience of the culture of the deaf community, ensuring a translation which includes this population's cultural and linguistic values;
3. before undertaking the back-translation, produce a synthesized version, based on the bilingual group's translation;
4. the back-translation should not be merely a transcription into the original language but should also include linguistic analysis of the syntax and semantics of each item;
5. the deaf individuals who do the signing should be fluent in Libras, producing the signs clearly, with appropriate use of signing space and good facial expression;
6. the development of the instrument in sign language should be recorded to guarantee reliable noting of the data.

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<sup>a</sup>Ministério da Saúde. Portaria n° 1.060, de junho de 2002. Aprova a Política Nacional de Saúde da Pessoa Portadora de Deficiência. *Diário Oficial Uniao*. 10 jun 2002.

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