



QUALITY OF LIFE IN DEAF SIGN LANGUAGE USERS IN SOUTHERN BRAZIL PSYCHOLOGICAL DOMAIN

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Abstract:

Introduction: Deaf users of Brazilian Sign Language (Libras) constitute part of a population who need to integrate and interact with other people in society. However, many Libras users are not able to communicate through spoken Portuguese and this may have an impact on their quality of life (QoL). Few studies have investigated factors that influence the quality of life of Libras users. **Objective:** To verify how a group of Libras users, who lives in the South of Brazil, perceive their QoL, especially in the psychological domain. **Method:** 60 deaf sign language users participated in this study by completing two questionnaires: 1) WHOOQL-BREF instrument in Portuguese written language and/or WHOOQL-Bref - Libras and 2) Identification questionnaire. The research was conducted from July 2015 to February 2016. **Results:** Of 60 deaf sign language users evaluated, 66,6% were female. The mean age was 28 years old, and most went to high school or college. Overall mean score on the WHOOQL-Bref scale was 43.3%. The Psychological domain have a score of 61,26%. **Conclusion:** Deaf sign language users have low results in the Psychological Domain when compared to hearing people research results. There is an association between the results in this

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domain scores with the lack of accessibility and interaction, negative thoughts and depression.

Keywords: deafness, psychological care, WHOOQL-Bref, quality of life

1. Introduction

According to the World Health Organization (WHO)¹, QoL is defined as “*an individual’s perception about their position in life, according to the cultural context and value systems in which they live and in relation to their goals, expectations, standards and concerns*”¹. The ability to communicate effectively through the use of sign language significantly undermines deaf people’s standard of living, their relationship with family and their social life^{2,3,4}. Besides the decrease of QoL resulting from linguistic, social, psychological limitations may cause serious problems to this population¹.

This article is a cross-section study carried out in Southern Brazil with deaf Brazilian Sign Language (Librasⁱⁱ) users that aimed to discuss how this population perceived their QoL². The complete scientific research of the researcher² showed the QoL of the deaf people, however in this article we will only discuss psychological issues of the deaf Brazilian people.

In this study an internationally recognized questionnaire – WHOQOL-Bref - was used. It covered several domains, but this manuscript will focus only on the results of the Psychological Domain, briefly conceptualizing mental health. It should be emphasized that this theme does not yet have a large coverage in Brazilian researches, and among the few found are those of Chaveiro and researchers³⁻⁵ and Garcia⁶.

These studies were the first to highlight the QoL of deaf Libras users in Brazil. The authors point out the need for more research in the area to measure QoL in this population. International research relating to QoL and the psychological condition with sign language users were made by some researchers⁷⁻¹⁷.

The psychological domain is defined, according to World Health Report (WHO)¹⁸ as “*the state of complete physical and mental well-being*”. According to WHO, studies have found that significant life events act as stressors and when they occur, they can predispose people to mental disorders and various physical diseases such as heart attack¹⁸. Such stressful events act in conjunction with others, such as genetic predisposition, personality and the ability to cope with life, can cause these disorders^{1,18}.

Thus, a study demonstrated that a person with weakened, depressed mental health, for example, has great difficulties to maintain loving relationships, performing duties at work and even raising children¹⁸. In addition, psychological problems can influence all family members in such a way that they can become addicted to drugs and alcohol, contract infectious diseases, develop allergies and autoimmune diseases¹⁸.

ⁱⁱ Libras is a sign language used by deaf people from Brazil.

The World Health Organization¹ stated that depression is the leading cause of disability with a 50% higher rate of burden of depression among women than men. It is a condition that presents co-morbid disabling conditions for people with hearing loss. A larger percentage of previous studies conducted among the population of individuals with hearing loss in Nigeria and other African Countries¹⁹, concentrated on the relation between stress and psychosocial issues. Other studies^{10,20,21,22} show that deaf people are more susceptible to diseases such as depression and stress.

Still, there are only few Brazilian studies relating deaf people's Libras users QoL. This study aims to verify how a group of deaf sign language users, who live in Southern Brazil, perceive their QoL with emphasis on psychological domain.

2. Methods

It is a quantitative study; data was collected by means of the application of two instruments: the WHOQOL-BREF²³, and a sample profiling questionnaire.

This research was carried out in Curitiba, a city located in Southern Brazil, capital of Paraná State, and in smaller towns around this capital city (Metropolitan Area) - São José dos Pinhais, Campo Largo, Pinhais and Colombo. Those towns were selected due to their proximity to the center where the research was performed, and due to the presence of many deaf people, sign language users. It is worth elucidating that, according to data by the Brazilian Institute of Geography and Statistics, 2015²⁴ there are over 2000 deaf individuals in the studied region.

This study was approved by the Ethics Research Board under number 50438915.5.0000.5529.

2.1 Participants

Sixty (60) deaf individuals participated in the research, and the inclusion criteria were: being deaf, sign language user, over 18 years of age, resident in Curitiba, Paraná State, and towns within its Metropolitan Area.

For the participants' selection, initially, institutions that attended deaf individuals, such as schools, universities, associations, religious institutions, located in the mentioned cities were contacted. Such institutions provided deaf individuals' names and contact of those who matched the research inclusion criteria. A researcher e-mailed the participants and explained the study goals and instruments, thus, those deaf individuals, who matched the research inclusion criteria, were invited to participate by e-mail or message.

2.2 Instruments

The WHOQOL-Bref questionnaire was selected for being an instrument objectifying the assessment of the quality of life, it was also translated into several languages and presents satisfactory levels of equivalence, so that results reliably reflect the actual quality of life of a given community in its transcultural use. In addition, this instrument

was selected for being the only Brazilian instrument with a validated version in the Brazilian sign language³.

That instrument comprises 26 questions about the respondents QoL, including health, other segments of their lives and their experiences in the four weeks prior to the study. All the items in WHOQOL-Bref have five answers' options, each ranging from the highest to the lowest score (5-1). The questions of the instrument entail diverse aspects of the daily life and approach four domains of QoL: physical, psychological, environmental and social relationships. The answers follow Likert scale (from 01 to 05), in which the higher the scoring, the better the quality of life²³.

To use the WHOQOL-Bref Libras, initially, one of the researchers e-mailed the researcher Chaveiro, who was responsible for the Brazilian validation of this instrument, requesting a "key" of the WHOQOL-Bref Libras software with its videos in order to use it. Chaveiro and researches⁵ developed a proper instrument to assess the QoL of deaf in their own language, justifying that it is easier for the deaf to answer in Libras, thus, having greater accessibility and clarity in their answers⁵.

It's important to notice that the WHOQOL-Bref Libras is a video instrument, so the questionnaire questions, instead of use the written language as in the original test, are made through Libras. This instrument was validated in Brazil in 2011³.

After that, a characterization questionnaire was also applied. This questionnaire asks questions about deaf people's sociocultural data, such as gender, age, salary, current employment or unemployment status, acquired training and schooling, and the use of Libras and Portuguese oral/writing language. The intention of the application of these two instruments was to draw crosses and comparisons between QoL and other factors that may influence it. Participants will be called S (subject) and a number from 01 to 60 represents the 60 deaf participants.

2.3 Analysis

The collected data was submitted to statistical analysis by means of descriptive statistical methods (tables of frequency, mean, standard deviation, minimum value, maximum value), and inference methods (Friedman's ANOVA and Statistical Tests - Chi-square Test and Fisher's Test), considering significance level of 0.05 (5%).

In the discussion below, it was opted to cross only some data from the WHOQOL-Bref questionnaire, especially in the psychological domain with the sample profiling questionnaire.

3. Results

The mean age of the 60 study participants was 28 years with a standard deviation of 9.97 years (minimum age 18 years and maximum of 58). Regarding the type of deafness, 91.67% (n = 55) of the participants answered that they had congenital deafness, and only 8,33% (n = 05) acquired. 30% (n = 18) of the sample indicated that they completed high school, 31.67% (n = 19) graduated in universities, 21.67% (n = 13) had postgraduate and

6.67 % (n = 4) of the sample concluded a Master degree. The profile of the participants, according to gender, salaryⁱⁱⁱ and schooling is represented by their absolute and relative frequencies in Table 1:

Table 1: Sample Profile (N = 60)

| Variables | Frequency | % |
|---------------------------|-----------|-------|
| Gender | | |
| Male | 20 | 33,33 |
| Female | 40 | 66,67 |
| Average age | | |
| 28 years old | | |
| Monthly Earnings | | |
| 1 - 2 Salary | 26 | 43,33 |
| 3 - 4 Salary | 13 | 21,67 |
| More than 4 salaries | 09 | 15,00 |
| Unemploeyed | 12 | 20,00 |
| Level of Education | | |
| Elementary | 06 | 10,00 |
| High school | 18 | 30,00 |
| University graduate | 19 | 31,67 |
| Specialization | 13 | 21,67 |
| Master | 04 | 06,67 |

Source: Data research.

Regarding the general questions, in the application of the WHOQOL-Bref, it was noticed that half of the sample (51.7%) evaluated their quality of life as good or very good, and 55% related to be satisfied with their health.

The mean scores obtained in each domain (physical, psychological, social relations and environment) of quality of life are presented in Table 2. For the organization of this table, Friedman's ANOVA test was applied with a significance level of 0.05 (5%), and it was possible to verify the existence of significant differences ($p = 0.0355$) between the results of the domains. The identification of differences shows significant results between the Environment and Physical domains ($p = 0.0085$), Environment and Psychology ($p = 0.0032$), Environment and Social relations ($p = 0.0069$).

When crossing the WHOQOL-Bref questionnaire with answers to the sample profile, it was found significance, showing that factors such as age, orality and writing can influence psychological domain. This confirms what had already been described in another study²², that is, if the deaf have access to a quality education and interact with their families through a common language, they will have a better QoL. Without this, young deaf people are at greater risk of engaging in health-damaging behaviors, such

ⁱⁱⁱ Brazilian minimum salary in 2019 is R\$ 998.00, equivalent to US\$260.00.

as tobacco use, alcohol consumption, illicit drug use, high-risk sexual behavior, and disease transmission.

Table 2: Mean and Standard Deviation Scoring of the QOL Domains

| Domains | N | | Mean | Minium | Maximum | Standard Deviation |
|----------------------|-----------|----------|--------------|--------------|--------------|--------------------|
| | R | N/R | | | | |
| Physical | 54 | 6 | 58.40 | 35.71 | 92.86 | 11.80 |
| Psychological | 57 | 3 | 61.26 | 29.17 | 91.67 | 14.13 |
| Social Relationships | 46 | 14 | 64.31 | 25.00 | 100.00 | 21.06 |
| Environment | 57 | 3 | 54.77 | 21.88 | 84.38 | 14.49 |

R = number of subjects who answered; N/R = number of subjects who did not answer.

Source: Data research.

The psychological score of 61.26 % is low when compared to people without hearing problems. A study with hearing people who lives in the northeastern region of Brazil, which is one of the poorest regions of the country, also applied this questionnaire with 930 adults attended in SUS^{iv}, and their average in this domain was 66.5%²⁵.

Another Brazilian study developed with 66 elders who live in the city of Pontal do Paraná, located in Southern Brazil, demonstrated that this population showed a total score of 77,38% in the psychological domain²⁶. And a research²⁷, which also applied the WHOQOL-bref questionnaire to eight patients undergoing cardiac surgery after hospital discharge and after 60 days, has demonstrated that their score in the psychological domain was 81,25%.

In this way, it is possible to notice in the study showed here that the psychological domain of the WHOQOL-Bref, when applied with deaf sign language users was low. Even for the participants who self-rated themselves as proficient users of oral and written language.

In table 3 below, some correlations between psychological domain scores and age, salary, school education, orality, writing and reading at the significance level of 0.05 (5%) are demonstrated. It was verified by Spearman's Correlation Coefficient, that there is a significant correlation ($p < 0.05$) in the cases marked with (*).

^{iv} The Unified Health System (SUS) is one of the largest and most complex public health systems in the world, ranging from simple care for the assessment of blood pressure, through Basic Care, to organ transplantation, guaranteeing integral, universal access and free for the entire population of the country.

Table 3: Correlation between Psychological Domain Scores and Age, Salary, School Education, Orality, Writing and Reading

| Variable | N | Correlation | |
|------------------------------------|-----------|---------------|----------------|
| | | Spearman (R) | P |
| Physical and age | 54 | 0,1800 | 0,1928 |
| Physical and salary | 54 | 0,1118 | 0,4210 |
| Physical and school education | 54 | 0,2213 | 0,1078 |
| Physical and orality | 54 | 0,0938 | 0,4997 |
| Physical and writing | 54 | 0,2583 | 0,0593 |
| Physical and reading | 54 | 0,1171 | 0,3992 |
| Psychological and age | 57 | 0,2641 | *0,0472 |
| Psychological and salary | 57 | 0,0232 | 0,8637 |
| Psychological and school education | 57 | 0,2073 | 0,1218 |
| Psychological and orality | 57 | 0,3199 | *0,0153 |
| Psychological and writing | 57 | 0,2871 | *0,0304 |
| Psychological and reading | 57 | 0,1493 | 0,2678 |

Source: Data research.

Chart 1: Psychological Domain

| | |
|----------------|---|
| Age | The greater the age, the better the Psychological aspect ($r = 0.2641$) ($p = 0.0472$) |
| Orality | The better the use of orality, the better the Psychological aspect ($r = 0.3199$) ($p = 0.0153$) |
| Writing | The better the use of writing, the better the Psychological aspect ($r = 0.2871$) ($p = 0.0304$) |

It's possible to notice in Chart 1 that factors such as age, orality and writing can influence the psychological domain significantly. Similar data was found in some researches^{22,14}, which demonstrated that if young deaf people have access to a quality education and interact with older deaf through a common language, they will have a better QoL. These young people need to have good interactions, because the lack of a common language can cause health-damaging behaviors such as tobacco use, alcohol consumption, illicit drug use, high-risk sexual behavior, and disease transmission²².

In the research presented here, it can be noticed that deaf people who self-rated themselves as proficient users of oral and written language are those who report higher rates of QoL. Another research¹⁴ also demonstrated the importance of investments in quality education and bilingual schools, so that deaf people can have more effective interactions and a better QoL. Some Brazilian's studies³⁻⁶ demonstrated that deaf people who have a more negative perception about their QoL are those who have less successful interactions. This may generate a certain vulnerability of the deaf to mental health problems, such as anxiety, depression, and increase of social isolation, which reduces their chances of perceiving their QoL as satisfactory.

4. Discussion

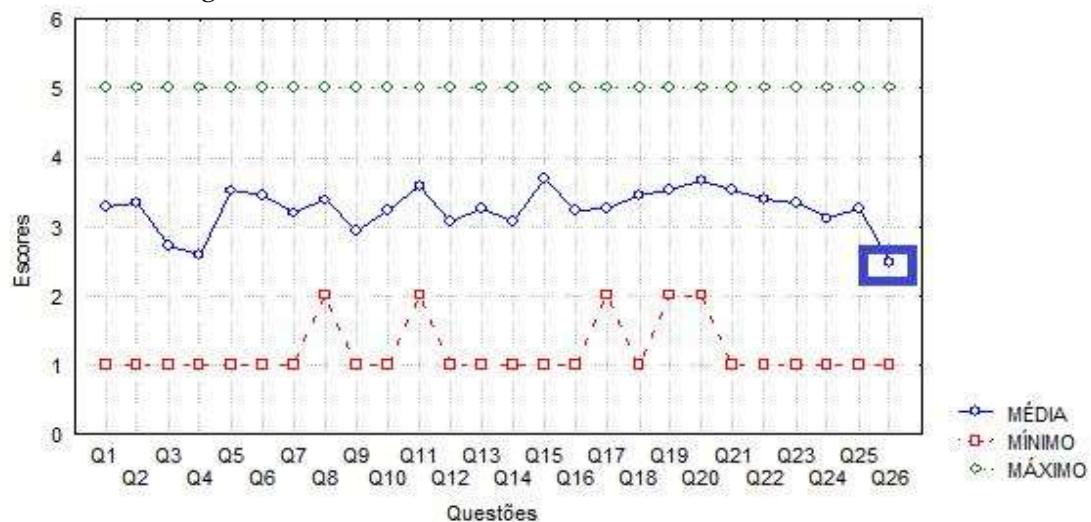
Hearing loss is an invisible disability that affects people of any age group from neonates to older adults. Hearing loss of any degree or configuration is capable of compromising communication, education, social functioning, and safety of the individuals. It is the greatest handicap which revolves around the development of communication skills, and also can be related with mental disorders and depression²⁸.

The psychological domain in the WHOQOL- bref scale has six questions, (Q5) How much do you enjoy life? (Q6) To what extent do you feel your life to be meaningful? (Q7) How well are you able to concentrate? (Q11) Are you able to accept your bodily appearance? (Q19) How satisfied are you with yourself? (Q26) "How often do you have negative feelings such as moodiness, despair, anxiety, depression?"

The first five questions had normal mean scores, but the question (Q26) "How often do you have negative feelings such as moodiness, despair, anxiety, depression?" had the worst score of the entire questionnaire. It can be assumed that many deaf people have negative feelings due to lack of a common language with the rest of the community in which they live, the lack of access to health professionals, etc²⁸.

In the Chart 2 below, the comparison between question (Q26) and the other questions in the questionnaire can be seen:

Chart 2: Average, Minimum and Maximum Results of the Questions Individuals



When comparing the low score presented above with other research²⁹, both demonstrated that deaf people frequently have negative feelings, such as anxiety, depression and despair. Another research³⁰ comparing deaf and hearing people mental health showed that deaf people have more depression symptoms. These authors reinforce that there are only few researches that refers to mental health in deafness, which is an aggravating factor for this problem.

One factor that can influence these negative feelings is the lack of communication at home. In our results, nine of the 60 participants answered that the use of sign language at home was "forbidden" by the parents. In addition, it is also worth noting

that only 25% of the sample said that they used Libras with their family and that among the most cited relatives, the mother ranks first. It should be emphasized that the figure of the father was not mentioned once as a Libras' user. Reports like this seem to demonstrate that there is still some prejudice regarding the use of the Libras by relatives.

This data corroborates with another study³⁰ that demonstrated that some of the deaf people's problems of communication and interaction are related to the lack of a common language with their families, which can cause psychological problems, such as stress and low self-esteem.

Regarding the use of Sign Language by families³¹, one study with family members of deaf children explain that many parents feel incapable to take care of a deaf child, and that they often seek for help, but do not receive the necessary information. This study revealed that many parents did not receive explanations about what deafness and its consequences were. The parents were also unaware of what Sign Language is, so they often opted for the oral model, advised by professionals who diagnosed deafness and guided families.

Another study²² also demonstrated that many young deaf people present depressive symptoms related to difficulties or almost non-communication with their parents. The convenience sample of this study had 230 deaf youths (mean age = 14.1, 24% were Sign Language users, 40% speaking only, and 36% using both LS and speech). The authors investigated issues related to communication, QoL and depression, and found out that deaf people who had better communication with their parents had lower rates of depressive symptoms.

The fact that the communication at home is inefficient can aggravate the psychological picture. Another Brazilian research⁵ found serious psychological problems related to deafness and demonstrated that the lower QoL scores are related to emotional and psychic factors.

In this same direction, a study²⁸ developed at University of Goteborg, in Sweden, with patients that have severe hearing loss and deafness, evaluated that a lot of deaf people have little support from their families due the lack of communication. The research results showed that the communication problems between deaf and their families were severe and can cause depression, anxiety disorders and/or trauma and stress related to mental disorders.

Another study³⁰ found that 75% of deaf people in Psychiatric Hospitals were not fluent in American Sign Language (ASL) and have psychosocial diseases. Comparing these data with hearing patients of the same hospital, it was found that there was a greater propensity to diagnose deaf patients with mood swings, anxiety, and other mental disorders.

Comparing the data from our research in the psychological domain with some international papers^{14,15,16,22}, it is possible to notice that the lack of communication can generate negative feelings and depression.

Our data also illustrates similar results to other researches^{22,29,30} which demonstrated that deaf people often suffer from depression or negative feelings, and some have difficulties getting specialized help, as health professionals, in general, do not use Sign Language.

This data, however, would require a more in-depth analysis that would consider also the non-deaf population, since some research indicates that psychosomatic diseases, such as depression, have become the evil of the century, and to cure this evil, specialized medicine and treatment in this area are required^{31,32}.

It is worth to observe that the current research has some limitations. One of them is that the sample comprised, coincidentally, deaf subjects who use Portuguese and sign language, thus the results must be considered within this context. Considering that there is no cut-off value defined as a reference for a better or worse QoL found in each domain of the WHOQOL-Bref instrument, the present findings should be considered as an isolated evaluation for deaf people who use sign language. It was also noticed that the WHOQOL-Bref questionnaire itself does not prioritize the individual aspects of the assessed subjects, such as hearing condition, and does not objectify to present causes for the lowest or highest scoring.

However, the present study, by means of correlations, enabled to raise new questions that may be related to better QoL, such as the use of Portuguese language, schooling and best salaries that deserve further investigation in depth in emerging countries.

5. Conclusion

The research had shown that the mental health of the deaf is a serious issue and there are only few researches that make this relation. The results demonstrated that deaf users of Libras perception about their QoL, especially in the Psychology Domain have low scores (61,26%). The lack of communication and a common language with families and in other environments can generate negative feelings, such as anxiety, despair, negative thoughts and depression.

Thus, the development of further research relating deaf people sign language users and QoL is important, to allow an adequate and reliable evaluation of this group of people. Deaf people's mental health should be considered while planning and implementing health promotion actions toward the studied community.

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