

ACCESS TO PRIMARY HEALTH CARE FROM THE PERSPECTIVE OF DEAF USERS

ACESSO À ATENÇÃO PRIMÁRIA À SAÚDE SOB A ÓTICA DOS USUÁRIOS SURDOS

EL ACCESO A LA ATENCIÓN PRIMARIA DE SALUD DESDE LA PERSPECTIVA DE LOS USUARIOS SORDOS

Ana Valéria de Alencar Amorim¹
Carla Vanessa Alves Alexandre²
Amanda Regina da Silva Góis³
Luciana Pessoa Maciel Diniz⁴
Rosa de Cássia Miguelino Silva⁵
Isabella Joyce Silva de Almeida Carvalho⁶

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Objective: To describe the communication perspective of deaf users of Brazilian Sign Language within the Unified Health System (SUS). **Method:** This is a descriptive study with a qualitative approach. Fifteen semi-structured interviews were conducted with deaf patients in Petrolina, a city in the Sertão region of Pernambuco. Data analysis was performed using textual data analysis software designed for qualitative research, employing descending hierarchical classification. **Results:** According to the described statements, the fragility of the quality of care provided to the deaf community was noted, evidenced by the lack of preparedness of professionals regarding knowledge of Brazilian Sign Language. **Conclusion:** This study describes the communication challenges faced by deaf people and has the potential to encourage the formulation and strengthening of existing public policies aimed at health equity.

Corresponding author: Carla Vanessa Alves Alexandre, carla.vanessa@upe.br

¹ Pernambuco University, Recife, PE, Brazil. <https://orcid.org/0009-0008-8745-369X>.

² Pernambuco University, Recife, PE, Brazil. <https://orcid.org/0009-0002-3922-6990>.

³ Pernambuco University, Recife, PE, Brazil. <https://orcid.org/0000-0003-4661-772X>.

⁴ Pernambuco University, Recife, PE, Brazil. <https://orcid.org/0000-0002-1774-3869>.

⁵ Federal University of Sergipe, Aracaju, SE, Brazil. <https://orcid.org/0000-0002-8705-4508>.

⁶ Pernambuco University, Recife, PE, Brazil. <https://orcid.org/0000-0001-8360-5897>.

Descriptors: Deafness. Sign Language. Primary Health Care. Equity. Unified Health System (SUS).

Objetivo: descrever a perspectiva da comunicação dos surdos usuários da Língua Brasileira de Sinais no Sistema Único de Saúde. Método: trata-se de uma pesquisa descritiva, de abordagem qualitativa. Foram realizadas 15 entrevistas semiestruturadas com pacientes surdos em Petrolina, cidade do Sertão Pernambucano. A análise dos dados foi feita por meio de um software de análise de dados textuais voltado para pesquisas qualitativas, mediante a classificação hierárquica descendente. Resultados: conforme as falas descritas, notou-se a fragilidade da qualidade da assistência prestada à comunidade surda, evidenciada pelo despreparo dos profissionais acerca do conhecimento da Língua Brasileira de Sinais. Conclusão: o estudo descreve os desafios comunicacionais enfrentados pelos surdos e possui o potencial de incentivar a formulação e o fortalecimento de políticas públicas já existentes, voltadas para a equidade em saúde.

Descritores: Surdez. Língua de Sinais. Atenção Primária à Saúde. Equidade. Sistema Único de Saúde.

Objetivo: Describir la perspectiva comunicativa de las personas sordas usuarias de la Lengua de Señas Brasileña (LSB) en el Sistema Único de Salud (SUS). Método: Estudio descriptivo con enfoque cualitativo. Se realizaron quince entrevistas semiestructuradas con pacientes sordos en Petrolina, ciudad del Sertão, Pernambuco. El análisis de datos se realizó mediante un software de análisis de datos textuales diseñado para investigación cualitativa, empleando una clasificación jerárquica descendente. Resultados: De acuerdo con las declaraciones descritas, se observó la fragilidad de la calidad de la atención brindada a la comunidad sorda, evidenciada por la falta de preparación de los profesionales en el conocimiento de la LSB. Conclusión: Este estudio describe los desafíos comunicativos que enfrentan las personas sordas y tiene el potencial de impulsar la formulación y el fortalecimiento de políticas públicas existentes orientadas a la equidad en salud.

Descritores: Sordera. Lenguaje de Señas. Atención Primaria de Salud. Equidad. Sistema Único de Salud (SUS).

Introduction

The Ministry of Health defines deafness as the inability or difficulty to hear⁽¹⁾. Data from the Brazilian Institute of Geography and Statistics (IBGE), from 2019, indicate that the deaf population exceeds 10 million people in Brazil. In the state of Pernambuco, the number of deaf individuals corresponds to approximately 523,055 people⁽²⁾.

Given this, through Law number 10,436 of April 24, 2002, the Brazilian Sign Language (Libras) was made official as a legal means of communication and expression. Libras is defined as a linguistic system of a visual–spatial nature, with an independent grammatical structure, which establishes the linguistic code originating from the Brazilian deaf community⁽³⁾.

However, even with the establishment and official recognition of Libras as a language, the current reality presents instability in the effectiveness of physician–patient communication. Ineffective transmission of information leads to the formation of doubts and insecurities regarding the medical conduct to be adopted⁽⁴⁾.

Highlighting McGuire's perspective, in the health context, it is not enough to transmit information; it is necessary to adapt to the patient's linguistic, cognitive, and cultural capacities for it to be effective⁽⁵⁾.

A study recognizes disability in a holistic manner and states that its effects directly interfere with social factors and must be observed from a broad perspective for the implementation of changes, such as in public health structures⁽⁶⁾. In this context, according to the National Policy for Hearing Health Care, within the Unified Health System (SUS) there must be improvements in management, dissemination of information, training, and continuing education of health teams at all levels—from Primary Health Care services to those of high complexity—in order to promote broad coverage in health care for the Brazilian deaf population⁽⁷⁾.

In health care for deaf patients, effective communication plays an essential role in ensuring safe and quality care⁽⁸⁾. Communicational accessibility is fundamental in this process,

as it helps minimize communication barriers between individuals and their environment⁽⁹⁾, in addition to fostering the formation of bonds between professionals and patients, relating to treatment adherence, symptom resolution, quality of life, seeking health services, and even patient mortality⁽¹⁰⁾. Carl Rogers' Humanistic Theory reiterates that patient-centered care, based on empathy, congruence, and positive regard, contributes to the creation of safe and welcoming environments, which are essential for the inclusion of deaf people in public health services⁽¹¹⁾.

Decree number 5,626/2005 continually affirms that the SUS must guarantee full health care for the deaf population, providing care with professionals trained in Libras or making interpreters available in these services⁽¹²⁾. The Convention on the Rights of Persons with Disabilities provides that individuals with any type of disability have a legal right to enjoy the highest attainable standard of health without discrimination. In this sense, signatory States are responsible for adopting measures that guarantee access to health services, adapting to the specificities of care in an individualized way⁽¹³⁾.

According to the Brazilian Law on the Inclusion of Persons with Disabilities, comprehensive health care for persons with disabilities is ensured at all levels of complexity, through the SUS⁽¹⁴⁾. However, the United Nations reiterates that barriers originate from environmental and attitudinal barriers⁽¹⁵⁾. In the same national law, these barriers are described as practices of negligence, exclusion, restriction, action or omission that harm, impede or nullify the rights of people with disabilities, including the refusal of adaptations and assistive technologies⁽¹⁴⁾.

As can be seen, even with legal support, the deaf community still faces numerous challenges to have full access to health⁽¹⁵⁾, since the availability of interpreter professionals is scarce and the presence of third parties during medical care can harm the confidentiality, individuality and autonomy of the deaf patients in their health-disease process⁽¹⁶⁾.

In view of the above, this study aims to describe the perspective of communication of deaf users of Brazilian Sign Language in the Unified Health System.

Method

This is a descriptive, exploratory study with a qualitative approach⁽¹⁷⁾, carried out between March and June 2023, in Petrolina, a city in the Sertão region of Pernambuco. The study is based on the international guide Consolidated Criteria for Reporting Qualitative Research (COREQ). The study participants were 15 users of the SUS (Brazilian Public Health System), whose inclusion criteria were: deaf people who use Libras (Brazilian Sign Language), over 18 years of age and who have already been attended at a Basic Health Unit (BHU) in the city, composed of Family Health Teams (FHT). Deaf people who, although deaf are able to speak, were excluded.

The sample selection was formed by convenience and the delimitation occurred through data saturation, a technique used in qualitative research, through semi-structured interviews, which considers that when no new element is found and no new relevant information is added, the data collection is considered saturated⁽¹⁸⁾.

The process was conducted in stages for the realization of the study; Initially, approval for the services was requested from the Municipal Health Department of Petrolina (PE), which has 57 Basic Health Units. Following this, based on information from the Health Department, an active search for deaf patients was conducted in the Basic Health Units that had deaf patients in their territory, through the Community Health Agents, who have the deafness reports attached to their Electronic Citizen Records (ECR), and the necessary invitations for participation in the research were made. After formal acceptance by the participants, interviews were scheduled and took place in the participants' homes.

Data collection was carried out through a semi-structured interview guided by a research instrument consisting of closed-ended questions

to outline the participants' socioeconomic profile, as well as guiding questions, namely: *How do you communicate with professionals at the Basic Health Unit (BHU)? Do you need a hearing companion? What does this mean to you? And what is your experience with care in Primary Health Care?*

After the participants authorized the study and signed the Informed Consent Form (ICF), the interview was conducted in a single meeting, in the presence of the participant and the researcher, through a video recording for data collection, using the video capture application on the researcher's smartphone. To conduct the interview, the researcher, who is also an interpreter, translated the questions into Brazilian Sign Language (Libras).

During the pre-analysis of the data, the interviews were transcribed into the Microsoft Word text editing software, and the contents were transcribed, organized, and coded to form the textual corpus of the research.

Data analysis was supported by the software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (Iramuteq), version 0.7 alpha 2, using simple classification of text segments (TS) through the Descending Hierarchical Classification (DHC), which categorizes the

most significant words into classes defined by chi-square tests. All grammatical morphological classes were included in the lexical analysis.

The DHC generates a graphic representation called a dendrogram, composed of classes that must be named from left to right, respecting the core meaning that emerges from the clustering of words in each class, in light of the appropriate theoretical framework⁽¹⁹⁾. Each named class had excerpts of speech attached to corroborate the core idea; the speech excerpts were extracted from the Corpus Coloré, a feature available in the aforementioned software.

This study complied with Resolution number 466/2012 and was approved by the Research Ethics Committee (REC) for studies involving human subjects at the Centro Universitário Integrado de Saúde Amaury de Medeiros (CISAM/UPE), Opinion 5,996,814.

To preserve participants' anonymity, codenames were used, with the letter "P" for participant, followed by a cardinal number identifying the document.

Results

After data collection, the socioeconomic profile of the participants was obtained, as presented in Table 1.

Table 1 – Distribution of socioeconomic variables of health service users. Petrolina, Pernambuco, Brazil – 2025. (N=15)

VARIABLES		n	%
Sex	Female	8	53.33
	Male	7	46.66
Age	18 to 36 years	12	80
	37 to 55 years	3	20
Education	Incomplete high school	1	6.66
	Complete high school	4	26.66
	Incomplete university education	2	13.33
	Complete university education	8	53.33
Marital status	Single	8	53.33
	Married	6	40
	Divorced	1	6.66
Number of children	No children	10	66.66
	1 child	3	20
	2 children	2	13.33

Source: author's own elaboration.

Among the deaf individuals interviewed, the mean age was 29 years. Of the 15 individuals, 8 are female and 7 are male. Most completed high school, and all attended a basic health care unit (BHU) within the last year and reported the need to go with a hearing companion to mediate communication. These people are usually mothers, siblings, or a sign language interpreter.

The textual corpus was analyzed using the DHC, divided into 123 Text Segments, which related 902 words that occurred 4,930 times. The DHC retained 84.55% of the total TS, generating

seven classes. Thus, after the analysis of the DHC through the corpus, the software schematized the classes in dendrogram format.

As recommended by the dendrogram, for the analysis and discussion of the classes, the partitions were followed from left to right. In this way, the classes were interpreted and named according to the core ideas they represented. Therefore, some classes were named individually, while some classes formed *groups of classes* due to the similarity of their core of ideas (Figure 1).

Figure 1 – Dendrogram of classes related to communication among deaf people in Primary Health Care.



Source: author's own elaboration.

Thus, they were named as follows: Class 3: Communication Failure, Class 2: Need for Fluency in Libras (Brazilian Sign Language), groups of

Classes 7 and 5: Support Network, groups of Classes 1 and 4: Communication Strategies, and Class 6: *Feelings of healthcare users*.

Box 1 – Word classes obtained based on the dendrogram and their retention percentages. Petrolina, Pernambuco, Brazil – 2025

CLASS 3	CLASS 2	CLASS 7	CLASS 1	CLASS 6	CLASS 5	CLASS 4
13.5%	14.4%	11.5%	18.3%	11.5%	14.4%	16.4%
Injection	After	To need	People	Professional	Mother	Deaf
Day	Until	Generally	Fact	To feel	Always	Thus
Person	To keep	Companion	To write	More	Together	Already
Home	Injectable	Listener	To depend	Fear	Brother	Very much
To take	To send	Reception	To try	Safe	Physician	To need
Tablet	Half	To	To get	Health	Never	Also
Nothing	Well	Mask	Nothing	Clearly	Problem	Important
To stay	To ask	Documentation	Time	Sign Language	Post	Now
To come	To take time	Mother	Gesture	To express	Alone	To want
To return	Itching	Always	To show	Example	To find	Why
To deliver	Pain	To arrive	Information	Better	Time	To ask
Medication	To write	Brother	Tongue	Explanation	To	Even
There	To answer	To happen	Letter	To know	Because	To call
To look	Get out	To ask	To solve	To give	To happen	Doubt
Medicine	Here	Post	Health Centers	Interpreter	Son	Bad
Father-in-law	Everything	Difficult	Exam	To get	To take	Like
Wife	Paper	Deaf	Difficult	To be	To explain	Reading
Question	Nurse	Problem	No	To stay	Orally	Son
To send	To wait	Physician	To understand	To explain	Sign Language (Libras)	Fact
To attend	To take	To show	Interpreter	Medication	Letter	Interpreter
Only	Gesture	Information	Paper	Orally	To solve	Communication

Box 1 – Word classes obtained based on the dendrogram and their retention percentages. Petrolina, Pernambuco, Brazil – 2025

CLASS 3	CLASS 2	CLASS 7	CLASS 1	CLASS 6	CLASS 5	CLASS 4
When	Just	To know	Alone	To understand	Health Centers	To exist
To pick up	To indicate	To search	To take	Thing	To take Care of	Difficult
There	Medicine	Husband	When	To want	In Brief	Then
Place	Yes	Medication	To be	Language	Busy	To ask
Accessibility	Okay	To put	To arrive	To know	There	Orally
Here	Father-in-law	Already	Nurse	To take care of	Today	Explain
Call	How	Communication	Half	Well	Furthermore	Exam

Source: author's own elaboration.

Discussion

Class 3 refers to Communication Failure. In the accounts of deaf patients, there is a reported failure to communicate, marked by encountering obstacles in primary healthcare services. This communication barrier between the hearing community and deaf people can contribute to feelings of social exclusion, inferiority, and other negative emotions:

I'm angry because everyone else can communicate and I can't. (P8).

Thus, in the face of non-existent or ineffective communication, the process of knowledge building in health is interrupted. The compromised quality of care leaves the patients full of uncertainties and doubts that directly interfere with their health-disease process; this demonstrates the absence of inclusive and holistic care.

I went and was left wondering: was he talking about an allergy or something else? But I couldn't express myself enough to ask. (P13).

Then people said it had to be 3, and I was like, 3 what? 3 days? 3 weeks? 3 months? I didn't understand, I was confused about that contraceptive. (P12).

The results found in the statements provided by the participants are consistent with data obtained in a study conducted by the Federal Statistical Office of Germany, which describes that deaf patients generally do not feel valued in the patient–physician relationship and report that their attempts to participate in their own

healthcare process are often not respected by medical professionals⁽²⁰⁾.

The frequent barriers that exist in communication between healthcare professionals and deaf patients are responsible for their lack of seeking medical care, even when clinically indicated, since this linguistic obstacle causes feelings of helplessness in deaf individuals and generates concerns related to being misunderstood by the physician⁽²¹⁾.

Class 2, defined by the *Need for Fluency in Libras*, addresses the essential nature of training in Libras for healthcare professionals. This proficiency can promote a sense of welcome and belonging within the deaf community. Furthermore, Libras supports the patient's independence, as described in the participants' statements, emphasizing the lack of privacy and the difficulty in being understood through sign language.

I dream that all professionals would know Libras (Brazilian Sign Language). Most aren't interested in learning it; they just want us to know how to speak orally. Because besides having privacy, we would understand our illness and the appropriate treatment. (P3)

Ideally, communication would be in Libras, so we wouldn't need to call interpreters, so the professional themselves would know Libras to give us privacy. (P4)

Physicians and nurses should be fluent in Libras; I dream of that. (P5)

For them [professionals], their language is Portuguese, so they communicate in Portuguese with hearing people, and communication flows. But if they don't know Libras, there is no communication. (P6)

The interpreter would find out things about my personal life; I would meet them outside, and sometimes I would

feel embarrassed. So, I prefer it to be just the physician and me. Ideally, they would actually know Libras. (P7).

The lack of knowledge of Libras compromises the quality of the care provided, since the flow of information is hindered both for the patient and for the professional, who is unable to transmit the essential elements for care. Consequently, ineffective communication can put the health of the deaf patient at risk and this situation highlights the need for Libras in the academic training of health-related programs⁽²²⁾.

The deaf community faces the deprivation of its rights when its primary language is neglected. The lack of preparedness and the professionals' unfamiliarity with Libras result in the formation of communication barriers, distancing deaf people from health services, as well as compromising the principles of autonomy and increasing dependence on intermediaries to enable communication between professionals and patients⁽²³⁾.

The group of classes 7 and 5, named Support Network, discussed the need for family support in enabling communication during health care, given that, in the absence of training in Libras on the part of professionals, deaf patients must bring hearing companions fluent in Libras so that they can be assisted at the health facility. The statements reported experiences of such health care, in which companions act as agents facilitating communication.

However, this dynamic reinforces the process of social exclusion experienced by the deaf community, compromises the users' autonomy in their care process, and contributes to health care that is prone to failures, considering that the communication mediated between the professional and the patient may be affected due to the lack of preparedness or incompetence of the support network.

Last year I went with my first child who was sick; I needed to take him to the physician, and it's very difficult to communicate. I always go with my mother; the physician talks to her, he tells her everything. (P12)

I always go with my mother. The physician explains everything to my mother, and I'm there wanting to know what's happening, wanting to know the details of every

conversation. But my mother can't explain everything. (P5)

They [family members] don't know sign language. I always go to the health center alone; I only take my mother or a friend if it's a serious matter. (P5)

Sometimes I go with my mother because she can communicate. I tell her what I'm feeling, and there she can communicate orally with the physician. He listens, examines, tells me what I can and can't do. (P11)

Whenever I go to the physician, I go with my mother. I can't understand alone. I have a kidney problem, so whenever I have a symptom related to it, my mother already knows, she helps me, and she goes. The physician explains things to her, and she tells me. (P14)

It's always my mother who goes, communicates with him [the physician] verbally, and I stay quiet and patient, just waiting, because there's no communication; I haven't found it to this day. (P15).

One of the research findings⁽²⁴⁾ corroborates the statements related to class groups 7 and 5, as it reinforces the fact that the strategies used to communicate with deaf patients prove to be ineffective, even when companions are present to mediate the care provided. Thus, to ensure equitable and inclusive healthcare, it becomes imperative to implement courses focused on the study of Libras during undergraduate training in health-related fields⁽²⁵⁾.

Although the inclusion of family members and friends as companions during appointments can facilitate the establishment of communication, it may nonetheless infringe upon the autonomy, individuality, and privacy of deaf users in healthcare services⁽²⁶⁾.

Class groups 1 and 4 are designated as Communication Strategies, and explore how Primary Health Care professionals seek to establish communication with deaf patients, as well as describe the tools used in the interaction dynamics in an effort to overcome existing linguistic barriers. Some of the participants' statements demonstrated the challenges and frustrations experienced by deaf individuals during this process, since attempts are generally flawed or ineffective.

She [the receptionist] was always speaking verbally and I didn't understand anything, so I decided to make a video call to an interpreter [...] he interpreted what I said to the person who was assisting me and interpreted what she said to me [...] The nurse spoke verbally, I explained that

I was deaf and she wanted me to lip-read. When I said I didn't know how, she made a complaining face. (P2).

It's very difficult, there's no communication. Many times I look for an interpreter, but I can't find one, I go alone and try to communicate by writing or through gestures [...] The nurse uses an app to communicate with me. She speaks verbally and the app signs for me. (P3).

She [the nurse] wrote everything down and I took the paper to the interpreter to translate. Most professionals only use gestures and we can't communicate. (P6).

Sometimes he writes and it's difficult handwriting that we can't understand. (P7).

Trying to communicate with gestures, they point here, they point there, and we don't really know what's happening. (P10).

There is no communication in the health centers. There are no physicians who can really tell us what we have, there are no interpreters, and since it's difficult to find one, I prefer to go alone, sometimes I write, sometimes I use gestures. (P13).

I told the physician I was deaf and then he asked me to write. I said it was difficult, that I wanted to communicate in Libras (Brazilian Sign Language), but he didn't understand. (P15).

From the perspective of comprehensive care, a study showed that health professionals generally resort to communication strategies that include writing, mime, gestures, visual representations through drawings, and the use of information and communication technologies, such as applications for translating signs into Libras⁽²²⁾. However, for the effectiveness of equitable care, communication between the deaf patients and the health professionals must be carried out in sign language.

A study corroborates the results of this research by stating that the strategies most commonly used by deaf individuals consist of the presence of a hearing companion during the appointment and the use of gestures/mime. However, most deaf individuals reported insecurities regarding post-consultation instructions⁽²³⁾.

The barriers encountered in communication between deaf patients and physicians at the health unit can be explained by the lack of proficiency in Libras among students during their undergraduate training. This result corroborates another study, which states that there is inadequate preparation in curricular offerings throughout the program, including insufficient

learning of sign language and inclusive care for deaf patients⁽²⁷⁾.

Class 6 refers to the *Feelings of users in healthcare* and presents reflections on patients' statements regarding the concerns, fears, and emotions that arise when they need to be attended to by health professionals who do not fully understand them.

It would be more comfortable if everyone knew sign language; we would take better care of our health without fear of taking the wrong medication. It's very dangerous to go alone. (P4)

There are times when I want to express myself, say what I'm feeling, and I can't because I don't know if he'll understand [...] If he [the physician] gave me explanations about the medication treatment in sign language, I would feel safer. (P7)

I sat there waiting. He [the physician] couldn't ask me things, and I couldn't say things. I was so scared that I froze. (P13).

With the absence of qualified professionals to provide care to deaf patients in health units, these individuals become dependent on the support and availability of companions in order to access healthcare. Thus, although companions contribute to mediating interactions between deaf patients and physicians, research findings indicate difficulties in the exchange of information due to companions' limited knowledge of Brazilian Sign Language (Libras), which contributes to feelings of anguish, frustration, and helplessness among deaf patients⁽²⁸⁾.

According to the Salamanca Statement, it is essential that deaf individuals use sign language as their primary means of communication, as the sign language of their country ensures effective communication with others, plays an essential role in the formation of personal identity, and fulfills a social, individual, and cultural function within society⁽²⁹⁾.

Among the limitations of this study, the lack of information on deaf individuals registered in the areas covered by the Family Health Strategy (FHS) teams stands out. Thus, triangulation with more than one translator is suggested for future studies. In addition, there were limitations in sample selection due to the small number of patients with a formal diagnosis of deafness who

communicate through Libras. Further research is recommended in order to give greater visibility to the needs of the deaf community and to identify measures that facilitate improvements in care and equitable access to comprehensive healthcare.

Moreover, the study contributes to strengthening the theoretical foundation for the development of more inclusive public policies aimed at creating and implementing welcoming and safe health spaces for the deaf community, as recommended by Carl Rogers' Humanistic Theory.

Final Considerations

The findings of this research show that the shortcomings in care, as reported by deaf participants, are mainly due to the lack of effective communication strategies and the unpreparedness of health professionals to attend to the deaf community, as they are unfamiliar with Libras.

Consequently, the participants' experiences in Primary Health Care revealed that all interviewees had difficulty understanding what FHS professionals were saying, and they expressed negative feelings about the care received. This factor reflects the quality of the services provided. Encounters with deaf patients may not be frequent; however, the barriers identified place the healthcare provided to deaf individuals at risk.

Thus, there is an urgent need for the training and qualification of health professionals—especially in the field of Nursing—in Libras, beginning in undergraduate education, as well as the implementation of permanent professional education initiatives, in order to improve deaf individuals' access to quality healthcare and ensure the basic health principles required by the SUS.

Collaborations:

1 – Project conception and planning: Ana Valéria de Alencar Amorim and Rosa de Cássia Miguelino Silva;

2 – Data analysis and interpretation: Ana Valéria de Alencar Amorim, Carla Vanessa Alves Alexandre, and Isabella Joyce Silva de Almeida Carvalho;

3 – Writing and/or critical review: Carla Vanessa Alves Alexandre and Isabella Joyce Silva de Almeida Carvalho;

4 – Approval of the final version: Amanda Regina da Silva Góis, Luciana Pessoa Maciel Diniz, Rosa de Cássia Miguelino Silva, and Isabella Joyce Silva de Almeida Carvalho.

Conflicts of interest

There are no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available in the article itself.

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