

## Unified Health System: accessibility of deaf people in the countryside of Bahia state

Sistema Único de Saúde: acessibilidade das pessoas surdas no interior da Bahia

Sistema Único de Salud: accesibilidad de las personas sordas en el interior de Bahia

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### RESUMO

A acessibilidade das pessoas surdas no Sistema Único de Saúde ainda é precária devido às barreiras de comunicação. O objetivo do estudo foi analisar o acesso e o atendimento ofertado à comunidade surda nos serviços de saúde públicos, no município de Vitória da Conquista, Bahia, por meio de uma pesquisa qualitativa. Participaram oito profissionais de saúde e treze usuários surdos, cujos dados foram coletados com aplicação de um questionário e um roteiro de entrevista semiestruturada. Os resultados, com base na análise do conteúdo, apontaram que não há capacitação, as Unidades Básicas de Saúde não apresentam estratégias de acessibilidade nos atendimentos, têm rara comunicação em Libras e um número reduzido de intérpretes – o que dificulta a comunicação entre o profissional de saúde e o usuário surdo. A formação em Libras e a presença de um intérprete são apontadas como estratégias para um atendimento de qualidade às pessoas surdas.

**Palavras-chave:** Sistema Único de Saúde; Usuários do SUS; Acessibilidade; Pessoas surdas; Libras.

### ABSTRACT

The accessibility of deaf people in the Unified Health System is still precarious due to communication barriers. The objective of the study was to analyze the access and care offered to the deaf community in public health services, in the city of Vitória da Conquista, Bahia, through qualitative research. Eight health professionals and thirteen deaf users took part in the research, whose data were collected using a questionnaire and a semi-structured interview script. Based on the content analysis, the results showed that

there is no training, the Basic Health Units do not have accessibility strategies in care, rarely communicate in Libras and have a small number of interpreters in their ranks – hindering the communication between health professional and deaf user. Training in Libras and the presence of an interpreter are identified as strategies for quality care for deaf people.

**Keywords:** Unified Health System; SUS users; Accessibility; Deaf people; Libras.

## RESUMEN

La accesibilidad para los sordos en el Sistema Único de Salud todavía es precaria debido a las barreras de comunicación. El objetivo del estudio fue analizar el acceso y la atención ofrecida a este público en los servicios de salud públicos, en el municipio de Vitória da Conquista, Bahia, con una investigación cualitativa. Participaron ocho profesionales de la salud y trece usuarios sordos, cuyos datos fueron recolectados a través de cuestionario y guión de entrevista semiestructurada. Los resultados, basados en el análisis de contenido, mostraron que no hay capacitación, las Unidades Básicas de Salud no tienen estrategias de accesibilidad, y tienen poca comunicación en Libras y reducido número de intérpretes – lo que dificulta la comunicación entre el profesional de la salud y el usuario sordo. La formación en Libras y la presencia de un intérprete se identifican como estrategias para la atención de calidad a los sordos.

**Palabras clave:** Sistema Único de Salud; Usuarios del SUS; Accesibilidad; Personas sordas; Libras.

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## INTRODUCTION

It is estimated that more than 10 million Brazilians have problems related to deafness, such as mild, moderate, severe, and profound deafness. Of this total, 2.7 million people are profoundly deaf – so they do not hear anything at all. The concept of deafness, in the light of medical knowledge, translates into a decrease in the acuity and perception of hearing; therefore, it is seen as a hearing impairment, which imposes difficulty in the natural acquisition of oral language. However, being deaf goes beyond the biological dimension, the physiological condition. It encompasses a becoming, a way of being in society, equipped with a cultural and social framework, as well as its own first language: the Brazilian Sign Language – Libras (IBGE, 2012; Levino *et al.*, 2013; Nóbrega *et al.*, 2012).

Supporting this statement is the definition in Decree 5.626/2005, in its chapter 1, art. 2: “A deaf person is considered to be one who, due to having hearing loss, understands and interacts with the world through visual experiences, manifesting their culture mainly through the use of Libras” (Brazil, 2005, own translation). In this way, the linguistic and cultural difference shapes the meaning of being deaf, as well as their relationship with the world.

Libras gained recognition as a legal means of communication and expression with law 10.436 of April 24, 2002. This was the deaf citizens first conquest in the quest to secure linguistic rights and equal conditions in society, whether in health, education, access to cultural goods, etc. As a result, sign language has become a tool for the empowerment of deaf people, enhancing their pursuit of equality (Brazil, 2002).

Regarding the deaf person’s access to health - to the Unified Health System (SUS) - we believe that deaf care also involves social inclusion. Equality and the right to health are guaranteed to all Brazilians by the 1988 Constitution of the Federative Republic of Brazil. For the deaf, these rights were reinforced through Decree No. 5,626/2005, which proclaims that the *SUS* and health care institutions must ensure full care for the deaf, with the training of health professionals in Libras or the availability of interpreters within these services (Brazil, 1988, 2005, 2021).

The *SUS* has three governing principles - universality, integrality, and equity - which together encompass the concept of inclusion of any person, with or without a disability, in the services provided, in line with federal decree no. 5.296/2004, known as the Accessibility Law. This decree establishes suitable conditions for the safe and autonomous use of the system by people with disabilities or reduced mobility. In this way, it identifies communication and information systems and media as essential strategies for guaranteeing accessibility, as well as defining which barriers to communication and information must be overcome (Brazil, 2004, 2008, 2021).

With this in mind, Law No. 13.146 - the Brazilian Inclusion Law - was published on July 6, 2015, which, in article 24, grants people with disabilities access to health services, reiterating, through article 3, the use of appropriate communication for the correct inclusion of people with disabilities, highlighting the importance of using Libras as an effective communication strategy and for the proper care of deaf people in the health care environment (Brazil, 2015).

As we can see, in terms of the law, much has already been achieved around rights for disabled people, including the rights of deaf people. However, analysis of the effectiveness of and compliance with these laws in the daily lives of deaf people reveals that there is still a lot to be done in the health sector. Scientific research on the themes of accessibility, inclusion and the health of deaf people provides accounts from these citizens, demonstrating how scarce and precarious these principles still are in health care (Neves *et al.*, 2016; Pires; Tigre Almeida, 2016; Souza *et al.*, 2017).

The challenge of caring for deaf people in health units is primarily because of the communication barrier. This explains why deaf patients turn to the health system less often than patients without hearing

impairments, pointing to fear, mistrust, and frustration as the main difficulties. Faced with these obstacles, deaf citizens are prevented from fully benefiting from health services that have the effective resources to assist them. It is essential to respect the specific nature of the use of Libras and other resources in the construction of effective communication for deaf citizens so they can be welcomed in health care (Neves *et al.*, 2016; Souza *et al.*, 2017; Tedesco; Junges, 2013; Brazil, 2021).

As pointed out by Levino *et al.* (2013), it is important to disseminate knowledge about Libras to contribute to the training of professionals qualified to understand the language and help with the specificities of this group. Many barriers and difficulties still need to be discussed and overcome so that deaf people can communicate fully and effectively in the healthcare environment. Therefore, it is the state's duty to provide for the deaf community, to pay attention to this outlook on communication and health, enabling the generation of results that have an impact on paradigm shifts in health professional communication and, consequently, on the life of a deaf person.

Despite being protected by law, the deaf community still encounters many obstacles and various difficulties in gaining full access to healthcare. This can be seen in published qualitative analyses with this target audience. It is therefore necessary to conduct more research on this subject, in order to assess the deaf community's current experience of the health system, from the perspective of these citizens, outlining positive and negative points, in order to identify the flaws and bring them to the attention of the scientific community so that the rights of the deaf are ensured.

According to the Association of the Deaf of Vitória da Conquista, there are around 300 deaf people in the municipality where this study was conducted, and according to the Vitória da Conquista City Hall website, there are around 471 deaf people in a population of 306,866 inhabitants. However, these figures are based on the services provided by these two institutions, as the last census did not specify the disabled population. Thus, no data was found regarding deafness classification - mild, moderate, severe, or profound deafness - in Vitória da Conquista, Bahia. The only classification available is that of deaf users participating in this study who have moderate and profound deafness. Classifying the types of deafness of the deaf population would be essential for the municipality to understand the needs of its deaf population, which depends on the *SUS* for health care.

The municipality of Vitória da Conquista is supported by municipal law No. 1.845, of July 19, 2012, which created the Municipal Council for the Rights of Persons with Disabilities and instituted the Municipal Conference for the Rights of Persons with Disabilities, which aims to monitor and evaluate the development of municipal policy and sectoral policies for the inclusion of this group. This law was regulated by municipal decree no. 14.672 of September 3, 2012, which establishes the social objectives of this council. These include drawing up plans, programs, and projects for the inclusion of the target group, proposing to ensure the effective implementation of objectives, as well as drawing up studies and research aimed at improving the quality of life of people with disabilities. Thus, research at municipal/local level has shown the importance of addressing the health perspective of the deaf community, reiterating the need for scientific production in this area (Vitória da Conquista, 2012a, 2012b).

In view of the above, the following research question arose: how does the deaf community in the municipality of Vitória da Conquista access the *SUS*? The main objectives of this study are to analyze the deaf community's access to and care received at *SUS* health services in the municipality of Vitória da Conquista, Bahia; describe the relationships between federal and municipal laws and the practical experience of deaf people in the municipality's health setting; identify the accessibility strategies used in Primary Health Care (PHC) aimed at deaf people in the municipality; describe deaf people's perceptions of accessibility, taking into account access to and healthcare in Vitória da Conquista; and identifying the perspectives of health professionals within Basic Health Units (BHUs) regarding care for deaf people.

## DEAF PEOPLE'S ACCESS TO *SUS* HEALTH SERVICES

Article 25 of Decree 5.626 of 2005 establishes that the *SUS* and companies that provide health services should guarantee comprehensive health care for deaf citizens at all three levels, and that, as of 2006, each service should carry out actions such as: prevention; developing hearing health; offering specialized care; selecting, adapting and supplying hearing aids where indicated; providing medical monitoring and speech monitoring, as well as speech therapy. This legal perspective is rooted in the biomedical view of deafness, in which this condition is conceived as a problem to be corrected, and the solution is health interventions to treat the deaf (Brazil, 2005; Nóbrega *et al.*, 2012).

In addition to these requirements, Decree No. 5.626 of 2005 states that deaf people must be cared for by professionals trained in the use of Libras or its translation and interpretation. Support is to be provided for the training and education of professionals in the *SUS* service network in the use of Libras. Furthermore, it establishes that families should be informed about the implications of deafness and receive clarification on the importance of introducing deaf children to Libras from birth, as well as to the Portuguese language (Brazil, 2005).

We emphasize that, after the diagnosis of deafness, it is essential that there is this dialogue between the doctor and the deaf person's family, because a lack of correct information and unfamiliarity with Libras and the cultural aspects of being deaf, can lead the deaf person's family to make choices that will not provide the child with access to Libras. The importance of this access in early childhood is highlighted, as it is ideal for ensuring the child's linguistic development, as well as relational aspects with others - their overall development. According to Strobel (2018), many health professionals consider deaf people from a clinical-therapeutic perspective, as if deafness needed to be repaired.

When dealing with access to health care for deaf people, Decree No. 5.626 of 2005 discusses the importance of deaf people's first language and their identity, cultural and linguistic backgrounds. In other words, the decree, in chapter VII, art. 25 (Brazil, 2005), stresses the need for adequate guidance for families regarding Libras and guarantees care for deaf people in the *SUS* network, as well as support for professionals in the *SUS* network to be trained in Libras. In this way, the effectiveness of the service offered to deaf patients will be based on linguistic accessibility. Therefore, the health professional must recognize the deaf person as a subject, with their specificities and as belonging to a community of their own, equipped with social and cultural contexts (Dizeu; Caporali, 2005; Nóbrega *et al.*, 2012; Oliveira *et al.*, 2015).

One of the biggest factors that interfere with the quality and adequacy of care provided by health professionals to deaf patients is a lack of awareness of who the deaf person is and their social and cultural context, associated with the inability to communicate non-verbally (DIAS *et al.*, 2017, p. 210, own translation).

Article 15 of the Statute of Persons with Disabilities states that a network of articulated, intersectoral services must be offered at different levels of complexity to meet the specific needs of this group. Article 18 also stresses the need to promote permanent training strategies for teams working in the *SUS* at all levels of care. Article 25 also states that health service facilities, both public and private, must ensure access to these places by removing barriers, using communication that considers the specific needs of people with sensory disabilities, such as the deaf population (Brazil, 2015).

However, even with the institution of the law to engender inclusion and accessibility for deaf people, there is still a substantial lack of preparedness regarding the welcome and health care provided for these people, especially in the medical context, which can lead to the removal of this group from the health service, as well as misdiagnosis and misconduct (Dias *et al.*, 2017; Pires; Tigre Almeida, 2016; Rocha *et al.*, 2017; Silva; Pachú, 2016).

## 2.1 Knowledge about deaf culture and the deaf community in undergraduate health courses

In view of the above, it is worth reflecting on how accessibility, inclusion and deaf culture are being considered and applied in professional training environments within undergraduate health courses. With the enactment of Decree No. 5.626/2005, Libras became a compulsory subject in higher education teacher degrees and speech therapy courses and became an elective subject in other courses (Brazil, 2005).

According to Decree No. 5.626, health courses can offer the curricular subject of Libras on an optional basis, meaning that knowledge about Libras, deaf culture and the deaf community is not mandatory in health professionals' training. The absence of obligatory training is not conducive to developing the skills needed to care for the deaf. It is essential for future health professionals to know the specificities of deaf identity and culture to develop communicative potential and foster the relationship between them and deaf patients. Understanding the components of the deaf person's identity and the cultural factors that shape the deaf community, as well as adequate communication and assistance, would strengthen the bond between the deaf patient and these professionals (Levino *et al.*, 2013; Rocha *et al.*, 2017).

It is essential that within undergraduate health courses deafness is understood in a way that goes beyond the biomedical concept of hearing impairment. As a result, students can realize that, for deaf people, deafness is an identity component. The deaf community fights for recognition of this identity. This conceptualization goes contrary to the biomedical view of adapting this condition to the hearing world (Nóbrega *et al.*, 2012).

It is therefore necessary to reflect on teaching Libras in university course curricula, since the discussions held in the classroom provide the foundations for future professionals who will provide care to the deaf in the course of their work. Thus, students need a lot of information and a solid linguistic foundation to establish communication with deaf people, as well as knowing the cultural specificities of deaf people.

## 2.2 Care for the deaf community in the SUS

According to Tedesco and Junges (2013), deaf patients turn to the health system less often than patients without hearing impairments, and the main reasons for this are difficulties, fear, mistrust, and frustration. By having to rely on other people to access health services and information, deaf people's citizenship is undermined.

The study conducted by Pires and Tigre Almeida (2016) analyzed deaf people's perception of the bond they establish with health professionals and the welcome they receive in health services. Twenty-six deaf people were interviewed and all of them said that the health units relied on written communication monitored by an accompanying person. A professional interpreter is rarely utilized as a communication strategy.

Pires and Tigre Almeida (2016) pointed out that deaf people do not have the opportunity to express themselves or to ask questions during consultations, and that the conversation is focused on the companion. Another relevant aspect is that the health professionals' questions are addressed to the companions, arousing insecurity, and indignation in the deaf interviewees since they feel annulled by the professionals' attitude. This attitude makes the deaf patient fear they will not be understood and may also receive an ineffective diagnosis.

The results of this survey showed that most health professionals did not use Libras to communicate. The deaf reported the urgent need for an interpreter to improve communication. This would make the interviewees feel more secure. Of the 26 deaf participants in the study, four had gone to the health service on their own and two reported feeling embarrassed. They said that they had many concerns and fears about the care they would receive from health professionals. The fact that most of them use written language does not enable deaf people to express themselves and be autonomous in their care. This situation deprives deaf

people of their right to individuality. Faced with these challenges, deaf people reported feelings such as sadness, anger, and disappointment at not being understood by health professionals who don't know how to communicate with a deaf person (Pires; Tigre Almeida, 2016).

Meanwhile, the study conducted by Dias *et al.* (2017) was based on 101 12th semester medical students, who were chosen because they were about to become doctors. A data collection instrument was used with seven questions regarding knowledge of deaf culture and accessibility in the care of these patients. The results showed that students about to graduate did not know Libras and few had any Libras language skills. When asked how they would treat a deaf patient, more than half said they would draw and/or mime. A small proportion would use a Libras interpreter and another participant said they would speak slowly so that the deaf person could lip-read. A small number of those who were proficient in Libras would use this language as their main form of communication. Almost 8% of them did not know how to proceed.

The study by Dias *et al.* (2017) found that, despite advances in the inclusion of deaf people in various Brazilian social contexts, there is still a significant lack of preparedness in relation to this group, especially in health, culminating in the neglect of these citizens. The study also reiterated that this lack of preparedness makes health professionals feel uncomfortable when they need to care for a deaf person.

Souza *et al.* (2017), in their literature review, found that the reality in health care services does not correspond to the legal requirements. According to the studies analyzed, in which deaf people and public health workers were interviewed, there are not enough interpreters or people who can communicate properly with deaf people. For this reason, most deaf patients need a companion, usually a family member, to get treatment from health services. The authors state that this communication problem makes it difficult for deaf people to seek medical care. As a result, most consultations end up taking place in a hospital environment, with a higher prevalence of hospitalization when compared to people without hearing impairments. The communication barrier impedes the preventive aspect of health care.

According to this research, this communication barrier often dictates the need for a third party to be present at medical appointments, which may be an interpreter, a family member, or a non-family member. This can jeopardize confidentiality, autonomy, and individuality in the treatment of deaf people. Health professionals' lack of knowledge about Libras leads to a lack of bonding with deaf patients, since their information and data is not passed directly to the person who needs and seeks the service (Souza *et al.*, 2017).

This is also emphasized by Dantas *et al.* (2014), who state that communication is a major obstacle for health professionals when caring for patients with deafness. For this reason, they propose that professionals recognize the shortcomings in communication and reflect on how to improve the service provided to this group accordingly.

Saraiva *et al.* (2017) point out that the right to health goes beyond social distinctions and must consider heterogeneity. However, in the day-to-day care of deaf people in health services what we see is a lack of communication, which persists despite the principle of equity in the *SUS*. This failure in communication excludes the deaf from their role in the process of developing health promotion, imposing dependence on third parties for minimally effective communication. In health care, this is due to the lack of training for professionals. As has been pointed out, this lack of training goes back to undergraduate studies, preventing satisfactory and inclusive therapeutic care, as advocated by the principles of the *SUS*.

In the studies analyzed, it was found that the lack of preparation of health professionals to deal with human diversity leads to the exclusion of these people and a distancing between health professionals, deaf people, and their access to services.

## METHODOLOGICAL APPROACH

This is a qualitative research project. A case study is used because it is a research method in which data from a reality are collected with the intention of explaining and describing the phenomena in the context in which they occur, based on their historicity and complexity (Triviños, 2009).

The data was collected at the Association of the Deaf of Vitória da Conquista and at three BHUs in the municipality of Vitória da Conquista - called BHU1, BHU2 and BHU3. The BHUs were chosen based on an analysis of documents made available by the municipality's Libras Interpretation Center, with the aim of finding the BHUs in the neighborhoods with the highest number of deaf residents per neighborhood. In the first instance, the management of each BHU was asked to authorize the Permanent Health Education Hub, and the project was presented. With the agreement of local management, a search for professionals interested in taking part in the research was conducted. They were given the choice of answering the questionnaire via a link provided by the researcher or via a printed document.

Thirteen deaf people referred by the Association of the Deaf of Vitória da Conquista and eight health professionals who worked in these BHUs took part in this study. The participants were divided into two groups: the first was made up of deaf people (*surdos*), referred to in the study by the letter S, followed by cardinal numbers - S1, S2 and so on. The second group was made up of health professionals, consisting of doctors, nurses, nursing technicians and receptionists, identified as health professionals (*profissionais de saúde*) - PS1, PS2 and so on. All participants had access to the Informed Consent Form (ICF), which was made available on the first page of the semi-structured interview script and the questionnaire.

The Association of the Deaf of Vitória da Conquista provided the contact details of the deaf people who were part of the association, and the initial selection of the deaf participants was made through an invitation by e-mail and WhatsApp text message. Thirteen deaf people agreed to take part in the research and were invited to learn more about the objectives of the study. The details of the research project were clarified with the support of a Libras interpreter from the Association of the Deaf of Vitória da Conquista. The interpreter translated the ICF data into Libras, recording an explanatory video. Following these explanations, the participants signed the informed consent form and began the interviews guided by a semi-structured script, translated into Libras by the interpreter.

The data was collected using interview scripts and specific questionnaires for each group of participants. Both instruments had fields for explanations and, at the end, a space for comments and testimonials. These fields were arranged as follows.

- For deaf participants: semi-structured interview script available on the Google Forms platform or printed out; divided into two sections containing personal data, followed by nine questions including multiple choice and open questions on health care, translated into Libras by an interpreter.
- For health professionals: a structured questionnaire made available online via the Google Forms platform or printed out; divided into three sections: personal data, professional performance, and questions about care for the deaf community, focusing on the professional's conduct, the team's conduct, and individual and collective training on the subject, including multiple choice and open questions.

The thirteen deaf participants had moderate and profound deafness, ten were female and three were male, aged between 22 and 42. In terms of educational level, four participants had completed high school and nine had completed higher education. Four reported having been exposed to written Portuguese language and chose to answer the printed form or the digital form through a link made available in advance via email or messaging application; for the other participants, the online interview approach was used, with



the direct support of the researcher and a Libras interpreter. The interviews were recorded and took place individually over two days, lasting around 15 minutes each. The answers were transcribed in the interview script with each participant identified (Table 1).

**Table 1 - Deaf participants and responses to the interview script**

Gender		Age group	Educational Level	Responded to the printed interview script or via the link	Online interview with interpreter
F	M				
10	3	22 to 42 years old	4 - High School	4	9
			9 - Higher education completed		

Source: Prepared by the authors.

Of the eight health professionals, five were female and three were male; three were doctors, three nurses and two nursing technicians, one of whom also worked as a receptionist at one of the BHUs. These professionals had been working in the health area for between three and 32 years. The health professionals also answered questions related to the length of time they had worked in the unit and their workload. The length of time they had worked at the BHU ranged from three months to 18 years, and their working hours ranged from three to eight hours a day (Table 2).

**Table 2 - Profile of the health professionals taking part in the study**

Gender		Profession	Length of service	Time working in the unit	Workload at the unit
F	M				
5	3	3 doctors 3 nurses 3 nursing technicians	from 3 to 32 years	from 3 months to 18 years	from 3 to 8 hours per day

Source: Prepared by the authors.

The data was analyzed by reading the questionnaires and transcribing all the interviews. Content Analysis (CA) was used, based on the studies of Franco (2008), to build categories considering the objectives of the study.

## RESULTS AND DISCUSSIONS

The data obtained from the two groups participating in the research, the responses of the thirteen deaf users and the eight health professionals, were analyzed in the light of the federal and municipal laws, as well as the existing theoretical framework. Based on this premise, the data was linked to the objectives of the study and analyzed with the support of the literature review, which is the result of research into the accessibility of deaf people to health services.

The data is described according to the categories of participants: deaf people and health professionals.

## Deaf people: access to and care given in *SUS* health services

In the interviews conducted with the thirteen deaf participants, it became clear that this group rarely goes to the BHU, even when they need to. This is because they do not have the accessibility they need to be welcomed and cared for.

When it comes to knowing about or attending a BHU, of the thirteen deaf people, eight reported that they used to go to a BHU. However, when asked where they go when they are sick, only one participant said that they go to a BHU; nine go to a private clinic first; and three go straight to the emergency service or to an Urgent Care Unit.

*Every time I go to the doctor it's very distressing because we can't communicate. I feel anxious and insecure [...].* (S5)

When asked who they usually go to these places with to seek medical or other professional help, six interviewees said that they go alone or with a friend, four with a relative or with a person without hearing impairments, and three said that they go with a Libras interpreter.

When it came to how they communicated during healthcare - whether with a doctor or another professional - each participant cited more than one form of communication: four answered "oral language"; seven, "written language"; four, "mime"; two, "through Libras/interpreter"; and seven said that they only communicated with their companion.

*When I go with an interpreter, it feels like it's the interpreter who's ill.* (S6)

*The doctor keeps writing [...], talking, and I can't hear, and he writes in Portuguese, so communication doesn't flow very well.*" (S3)

Tedesco and Junges (2013) noted that communication tools in this context are based on writing, the presence of a family member or companion and the use of gestures. When comparing questions about communication strategies used by both groups the answers complement each other. In the answers given by the health professionals, we have the following reports, which are in line with the studies by Tedesco and Junges (2013) and Pires and Tigre Almeida (2016).

*I write for the deaf person to try and understand.* (PS3)

*I need a third person to enable communication.* (PS1)

With regard to the use of writing as a strategy for communicating with deaf people, it's worth noting that although the natural or mother tongue of deaf people is Libras, language 1 (L1), and the Portuguese language is language 2 (L2), many deaf people have delayed access to Libras because they didn't experience a facilitating linguistic context in the early stages of language acquisition.

Pires and Tigre Almeida (2016) found that writing was used as a means of communication by health professionals. This shows a lack of preparation in providing adequate care to the deaf community. As stated earlier in this study, the communication strategy is neither the most effective nor the most appropriate for deaf people to feel well cared for.

Abreu *et al.* (2015) argue that the presence of a third person in the consultation can generate fear that personal matters will be revealed. There is also a fear that decisions and practices will not be passed on reliably. In line with this, Sousa and Tigre Almeida (2017) state that the presence of a companion affects the deaf person's citizenship, as it interferes with their autonomy, preventing them from having access to information that would help them to improve their quality of life.

When asked about the quality of care received at the BHUs they usually frequent, the answers were as follows: four deaf participants reported that they considered the care to be very poor; one considered it to be poor; one, very good; one, good; and six considered the care to be average.

*I get this feeling inside me; I know there's not going to be any communication. I leave the house knowing that there won't be any communication, wondering if he's going to write any words that I know, which is very bad. (S10)*

The thirteen deaf participants were asked to give a qualitative account of their perception of the health care they received. They reported that the doctors do not speak Libras:

*Health professionals need to learn Libras, communication for the deaf. (S13)*

They commented that there was a lack of empathy and that the service was more focused on the companion than on them:

*[...] It feels like I'm not there. I don't know what they think, they don't look at the deaf person. They don't explain, they don't make things clear. (S12)*

They also reported that health professionals do not use the technologies available to deaf people:

*1[...] I think all doctors should subscribe to the ICOM app. (S4)*

*In other places, the deaf are already getting help from ICOM, [...] this would make the deaf less insecure. And again, I say, if the doctor doesn't know sign language, you can use strategies like ICOM. [...] It's very different from the doctor moving his mouth towards you. (S6)*

As for accessibility strategies available at the BHU or other places where they sought health care, twelve deaf participants (around 92%) reported that there were no strategies of any kind and that the only means available to them was written language.

*No strategy, just a lack of communication. And there needs to be, urgently! Doctors need to know that Libras exists, that there are deaf people. (S9)*

Regarding health professionals having used communication in Libras when providing care, only one deaf participant reported that it was always in Libras, two said that this strategy had only been used once, and the vast majority - ten deaf people - reported that they had never received care in their first language.

*They don't communicate in Libras; they just write and that's it. And Portuguese for the deaf is complicated, difficult. Portuguese is a second language for us, it's difficult. Our communication is visual, it's easier." (S10)*

When asked: "Do you feel welcomed and cared for when you seek medical help, whether in the emergency room or at the BHU?", seven answered: "I feel very poorly cared for"; three answered: "I feel poorly cared for";

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1 ICOM is an app that translates Libras into Portuguese in real time through a videoconference. It can be downloaded to cell phones, tablets, notebooks, and desktops. ICOM is aimed at companies and public authorities, groups concerned with guaranteeing deaf people the right to receive care in their own language (Assessoria..., 2019).

and only three said: “I feel well cared for”. After these answers, they were asked to describe what feelings were aroused in them during the consultations. In general, they reported feelings of insecurity, fear, and anguish:

*Insecurity due to lack of Libras. (S1)*

*I feel insecure when the doctor doesn't understand what I'm saying and I don't understand back, there's no communication. (S3)*

*Every time I go to the doctor it's very distressing. Because we don't communicate, I get anxious and insecure (S5)*

*I'm all alone and I can't explain, the doctor doesn't understand what I'm saying. It's very difficult and tricky for me. (S11)*

Souza *et al.* (2017) and Silva *et al.* (2021) showed that the communication barrier impedes the preventive aspect of health care. In their study, Cavagna *et al.* (2017) stated that the lack of communication means that deaf people seek out health institutions in cases of extreme need. This was also seen in the responses obtained from the deaf users who took part in this study, because when asked which services they seek first when they are ill, most of them mention emergency and urgent care services.

### **Health professionals: access and care offered in SUS health services**

The health professionals answered 12 questions about care for the deaf community, undergraduate training to work with this group, in-service training to work with deaf patients, as well as evaluating the service provided to deaf users at the BHU where they worked. The answers to the questions were multiple choice and subjective.

The first question was: “Have you ever treated deaf patients at this BHU?”, and 60% of the health professionals had not cared for any deaf patients.

*[...] I've never come across a deaf person in this unit. (PS6)*

This gap between what the law says and the daily practice in the BHUs reflects the misconception among health professionals about a low need for health care among deaf people in these places, i.e., that there are few deaf people in the area, or even that deaf people do not need specific health care. When it came to their opinion of the care provided to deaf people at the BHU where they worked, the answers ranged from fair, poor, and very poor.

*Very bad. Because we're not prepared to deal with this group. (PS3)*

*Bad. Professionals are not trained to deal with this group. (PS5)*

*[...] Poor communication because I haven't been trained in Libras. (PS7)*

They said that there is little demand from deaf users, that there is a lack of training for the team of health professionals to deal with this group, that there is a lack of Libras interpreters in the units and that there is also a lack of time for one-to-one consultations.

*I don't know deaf sign language. (PS2)*

*The unit is generally very busy, which reduces the capacity for individualized care, especially when special attention is required. (PS8)*

When asked whether the BHU where they work has any strategy to make the environment accessible to deaf people, the response was unanimous, as 100% of the professionals stated that there was no accessibility strategy for deaf users in their BHU. Given the negative responses, the professionals were able to recommend some strategies to be implemented. Once again, they were unanimous in emphasizing the importance of having a Libras interpreter in the unit to accompany the care.

*I need a third party to facilitate communication. An interpreter or family member. (PS1)*

An important parallel can be drawn between the interviews with deaf users and the responses obtained from health professionals. Most of them suggested the presence of an interpreter or an employee trained in the use of Libras as a strategy to improve accessibility and effectiveness in communication to deaf users in health services. This strategy is provided for by Decree No. 5.626/2005 (Brazil, 2005), but it is clearly not put into practice, which hinders the process of interaction between deaf people and basic health care. This has been highlighted by Souza *et al.* (2017), who, in their literature review, found that the reality of health care services does not correspond to what is recommended by law.

When asked about their academic training - whether they had studied any subject or curricular component that addressed deaf people's accessibility to health services, two professionals answered yes, and 75% of the health professionals answered no. Looking further into the issue of academic training, all the health professionals, including the two professionals who had had engaged with a subject aimed at assisting deaf users, said that their initial training was flawed, as subjects with a reduced number of hours did not consider the specific nature of the deaf community.

When asked if, during their professional career, they had received any incentives from the federal government to be trained in caring for deaf people, 100% of the health professionals replied that they had not received any training in this area.

Regarding the communication mechanisms they used to assist deaf users, the answers were varied, as they could provide more than one response: one used oral language; six, written language; three used mime; only one used Libras/an interpreter; and six used communication with the deaf user's companion.

At the end of the questionnaire there was a question for health professionals to suggest strategies for changes to improve accessibility for deaf patients in the BHUs. The majority pointed to training health professionals in Libras or the availability of an interpreter or an employee who could communicate in this language.

When asked about the existence of strategies to promote accessibility for the deaf community, all the health professionals said there were no strategies. They also said that there is no team discussion about what is needed to care for the deaf.

Given this background, it is important to analyze the welcome given to deaf people in these services. It has been shown to be deficient, due to a lack of accessibility, which ends up alienating this group from PHC.

As pointed out by Reis and Santos (2019), there is restricted accessibility that breaks the universal right to health, going against the perspectives outlined by PHC. Some authors have emphasized that there is still a significant lack of preparedness when it comes to welcoming and providing health care to people with hearing loss, especially in the medical context and that this is likely to lead to this group disengaging with the health service, as well as causing misdiagnosis and misconduct (Dias *et al.*, 2017; Pires; Tigre Almeida, 2016; Rocha *et al.*, 2017; Silva; Pachú, 2016).

This environment causes deaf users to feel abandoned in health care settings, stirring up bad feelings such as anguish, fear, and anger, as evidenced in the testimonies of the deaf participants in this research. In this respect, Cavagna *et al.* (2017) point out that this group feels mistreated and discriminated against, since their needs are not met. As highlighted by Pires and Tigre Almeida (2016), deaf people do not have the opportunity to express themselves, nor to ask questions during consultations.

*There is no accessible service of any kind, neither private nor public, even if you pay, we don't have accessibility. It's as if they treat us with contempt. They don't show us anything, they don't explain anything to us, they just give us a piece of paper and say: "Go away". It's very sad [...]. You get there and ask something, you just sit there, without any kind of communication. They don't ask if you're deaf, if you have a companion [...].* (S9)

Soares *et al.* (2018) state that the tools used to establish communication are individual and specific. In this respect, there is a fragmentation of accessibility actions that promote the acquisition of solid attitudes in promoting accessibility, when in fact, these actions and strategies should be the result of a general framework, drawn up in public policies and implemented by managers, with the help and participation of health teams.

This is also noticeable in the participants' statements, in which loose strategies are mentioned, but are not the result of a unified approach to promoting accessibility. A quite common theme in several interviews with deaf users is the suggestion to use the ICOM app as an alternative for introducing Libras into health care at the BHU and in other health services.

*Deaf people in other places such as Salvador already have the help of ICOM, so the deaf person feels less insecure. [...] If the doctor doesn't know sign language, he can use strategies like ICOM [...] it's very different from the doctor moving his mouth towards you.* (S6)

Since Libras is not a compulsory subject in health courses, the difficulty of communicating with deaf people is reflected in the day-to-day lives of professionals who are faced with situations that make it clear how difficult it is to maintain an effective and adequate dialog. Furthermore, contrary to the decree (Brazil, 2005), the state and municipal apparatus does not provide these professionals with training in Libras, nor do they provide interpreters for this language in these services.

It is clear, therefore, from the answers obtained through the questionnaire addressed to health professionals, that there was no training during their undergraduate studies and that this shortcoming has not been corrected since their graduation. It is also important to note that successful communication and adequate patient care, in the context of deafness, determine whether the professional can adapt to the patient's own needs and situations (Dizeu; Caporali, 2005; Nóbrega *et al.*, 2012; Oliveira *et al.*, 2015; Pereira *et al.*, 2020; Silva *et al.*, 2021).

In an informal conversation with the staff at the units, some employees commented that it is exceedingly difficult to care for deaf people. For this reason, they try to deal with their needs as quickly as possible, to avoid contact with the deaf person. As pointed out by Tedesco and Junges (2013), health professionals feel uncomfortable when dealing with a deaf person, and this is reflected in their reports:

*We have no training to deal with this group. We feel quite lost.* (PS4)

Silva *et al.* (2021) stated that the lack of preparedness among health professionals means that the quality of care is impaired. That is why it is essential that they know Libras, to understand the deaf population

and not to jeopardize their health care. The basic training course for health workers is called Accessibility and principles of SUS. Comments arising from this course allude to deaf people's needs and corroborate the assertion that deaf people leave the consulting room feeling unsure about the procedures that should be conducted, about which medicines to take, how and when. To this end, the course addresses the Deaf Health Guidance Unit (NOSS) which is a valuable tool for taking action on these issues, as it enables the deaf to receive effective treatment through simple and clear communication measures, such as the use of Libras. An example can be found in the statement of one of the deaf participants (Fiocruz, 2020).

*[...] They don't want to use any kind of technology; they don't make an effort with the deaf. (S10)*

In the absence of effective and adequate communication, the health professional runs the risk of providing the deaf patient with ineffective treatment - which can lead to greater risks and damage to the user's health, according to S3:

*I feel insecure when the doctor doesn't understand what I'm saying and I don't understand back, there's no communication. (S3)*

Cavagna *et al.* (2017) addressed the importance of this communication and stated that by establishing communication with the patient, the professional can understand them in a holistic way, also grasping their worldview. And this effective communication prevents errors in care. In this sense, the provision of Libras learning tools for health professionals would provide inclusion in the care of the target audience. Soares and other researchers (2018) warn that, in addition to possible misdiagnoses, miscommunication makes it difficult to fill out medical records properly and provide effective treatment.

Saraiva *et al.* (2017) point out that the failure to train health professionals encourages the exclusion of deaf people from active participation in the health care process. This lack of training, which stems from academic education, means that communication is flawed and ineffective, with mimicry and gestures that make it difficult to provide satisfactory and inclusive therapeutic care, as the *SUS* principles state. The accessibility that should exist in health services is thus undermined, and there are no effective strategies to ensure and promote this right. Souza *et al.* (2017) state that these obstacles in health care, created by a lack of accessibility and a failure to humanize the doctor-patient relationship, are aggravated by deaf people's low knowledge of health-disease processes, as well as the difficulty they have in integrating into other sectors of society.

This lack of training subsequently leads to limited knowledge about deaf culture and the deaf community. This makes it difficult for health professionals to understand deafness from the perspective of the deaf, as pointed out by Nóbrega *et al.* (2012), because for the deaf, deafness is an identity component, and the deaf community fights for recognition in this sense. Bernardo *et al.* (2021) support Nóbrega *et al.* (2012) by arguing that learning Libras and integrating with the deaf community adds value to health professionals' training, enabling them to develop critical and reflective analyses and social engagement.

Health professionals should recognize the deaf person as a subject, belonging to a community of their own, with a social and cultural context. Professionals should reflect on human diversity to reduce the barriers imposed on those who are different. Consequently, they should work to raise awareness of the implications of deafness, seeking to overcome these obstacles to provide humanized care to this group of people (Dizeu; Caporali, 2005; Nóbrega *et al.*, 2012; Oliveira *et al.*, 2015; Silva *et al.*, 2021).

In this sense, health professionals can fall into the trap of ableism, putting the deaf person in a position of fragility and incapacity. This mistake can be illustrated by S12's statement that:

*They don't understand that I'm a logical person, I can understand [...]. (S12)*

When analyzing the health environment experienced by the deaf participants in this study, as well as the current literature, we see that these citizens are provided with restrictive PHC that does not respect the diversity of needs and the demands of this group. In this respect, beyond the healthcare sector, the social inclusion of deaf people begins much earlier, and depends on the population being prepared to welcome and interact with this community and the rest of society. Thus, fostering accessibility goes beyond training, it involves raising awareness of the needs of the deaf community and the importance of individuality to provide humanized care.

For this reason, it is essential that public managers commit to the ongoing training of professionals, so that they can meet the demands of deaf patients in a qualified manner. It is therefore important that responsibility for health professional services is given to managers and political actors in the context of inclusive access to health for the target group. It is also essential that in addition to other training and implementation, all sectors work on creating a practical manual with signs for the health environment, to facilitate and promote professional training. This would be a significant step forward in the dissemination of Libras within deaf people's health care processes (Dantas *et al.*, 2014; Pereira *et al.*, 2020; Saraiva *et al.*, 2017; Silva *et al.*, 2021).

## FINAL CONSIDERATIONS

This study analyzed and discussed accessibility strategies, or the lack of them, in the practice of health care for the deaf community in BHUs. It considered the points of view of deaf users and health professionals taking into account legal provisions and existing studies on this issue. This process provided an opportunity to reflect on the failures and shortcomings that exist in promoting the health of this group, which made clear the absence of public authorities in implementing the rights and duties guaranteed by Decree No. 5.626/2005 and Law No. 13.146/2015 (Brazil, 2005, 2015).

The results of this research brought to light a number of factors that contribute to maintaining an inaccessible environment, which does not promote the welcoming and inclusion of deaf people. These factors extend from the training of health care professionals to the negligence of public institutions in offering and promoting the training and specialization of these professionals in relation to the need for dialogue and understanding of Libras and knowledge of the cultural and linguistic contexts of the deaf community.

The production of this study expanded the scope for listening to deaf people by creating opportunities for debate and statements about the experiences of each of the participants in the health services. The research also made it possible to awaken and change the outlook of the health professionals invited to reflect on this issue, through questioning that may have taken them out of their comfort zone, by promoting self-criticism and debate on both individual and collective action in promoting the health of the deaf community. It can also be said that the work indirectly promoted changes to actions and the implementation of new ways of looking at care for the deaf and their particularities. It was an invitation to promote health and provide a welcome with accessibility and empathy.

A lack of organized and available data on the population distribution of deaf people by neighborhood in the municipality was one of the limiting factors in this research. This made it difficult to choose the BHUs where the deaf participants were usually cared for. The units were chosen using estimates obtained from the Association of the Deaf of Vitória da Conquista data. This estimate did not correspond to the data collected from the deaf participants. Another limiting factor was the workplace dynamics of the BHUs, which made it difficult to access more health professionals and, consequently, was reflected in the number of professionals taking part.

For the deaf community, this research has brought hope for a change in the way society views the deaf. It allowed deaf people to discuss and vent about the difficulties and limitations they experience in health services. We hope that, gradually, the actors will be able to reflect on a more humane and inclusive academic education.

With regard to the health courses at the Multidisciplinary Institute of Health at the Federal University of Bahia (IMS/UFBA), it is hoped that these results will make it possible for students to immerse themselves



in two different perspectives on the same subject: that instigate the feeling of change with the aim of taking this debate to the scientific environment, in order to enforce the law and the rights of the deaf community in the health sector; and that it becomes clear how fundamental it is to study Libras and the cultural issues of the deaf community that impel the training of doctors who are more attentive to accessibility and concerned with the integrality of care for all people, without exception.

Finally, this research shows that there is still a lot to be studied on this subject. More research and analysis into the various health sectors as well as the promotion of concrete actions with a view to caring for deaf people are needed by both the deaf community and in scientific literature. Thus, this study is just one grain in a universe of other problems that must be analyzed and debated to improve the quality of life of people with deafness.

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