

## Health care provided to people with hearing impairment: reflections based on the patient's experience

### Assistência em saúde prestada a pessoas com deficiência auditiva: reflexões a partir da experiência do paciente

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**ABSTRACT | OBJECTIVE:** To discuss health care for people with hearing impairment, based on the patient's experience. **METHOD:** Descriptive study, case report type, with reflective analysis. The report was made by a deaf person, with a high level of education and a keen critical sense, in an academic seminar. In view of the richness of the content reported, she was invited to do so in writing, with a view to its publication, and thus contribute to advances in care. The narrative analysis was comprehensive, based on the theory of narrative structural analysis. **RESULTS:** The participant's experiences in the health services are marked by feelings of anguish and fear, and of non-compliance with the needs presented, resulting in dissatisfaction. The lack of preparation of professionals to communicate with deaf people hinders interactions and health education actions, which are essential for learning for self-care, leaving them vulnerable to risks and situations of illness, in addition to reinforcing social exclusion. **CONCLUSION:** Health professionals need to rethink care considering the specificities of people with disabilities, in order to provide inclusive health care capable of meeting the singularities of this group. To do this, they need to be trained. Undergraduate health courses also need to improve professional training by contemplating the characteristics of people with disabilities in the contents covered.

**KEYWORDS:** Nursing Care. People with disabilities. Patient-centered Care. Hearing Loss. Health Education.

**RESUMO | OBJETIVO:** Discorrer acerca do atendimento em saúde voltado a pessoas com deficiência auditiva, a partir da experiência do paciente. **MÉTODO:** Estudo descritivo, do tipo relato de caso, com análise reflexiva. O relato foi feito por uma pessoa surda, com alto grau de escolaridade e senso crítico apurado, em um seminário acadêmico. Diante da riqueza do conteúdo relatado, ela foi convidada a fazê-lo por escrito, visando sua publicação, e com isso, contribuir para avanços na assistência. A análise da narrativa foi do tipo compreensiva, fundamentada na teoria da análise estrutural de narração. **RESULTADOS:** As vivências da participante nos serviços de saúde são marcadas por sentimento de angústia e medo, e de não atendimento das necessidades apresentadas, resultando em insatisfações. O despreparo dos profissionais para se comunicar com pessoas surdas dificulta as interações e ações de educação em saúde, essenciais ao aprendizado para a o autocuidado, deixando-os vulneráveis a riscos e situações de adoecimento, além de reforçar a exclusão social. **CONCLUSÃO:** Os profissionais de saúde precisam repensar o atendimento considerando as especificidades das pessoas que possuem deficiência, a fim de propiciar uma atenção em saúde inclusiva e capaz de atender às singularidades desse grupo. Para isto, precisam ser capacitados. Os cursos de graduação em saúde também precisam aprimorar a formação profissional contemplando as características das pessoas com deficiência nos conteúdos abordados.

**PALAVRAS-CHAVE:** Cuidados de Enfermagem. Pessoas com Deficiência. Assistência Centrada no Paciente. Perda Auditiva. Educação em Saúde.

## 1. Introduction

It is known that health is a constitutional right of all citizens, as provided in the Brazilian constitution, a right that includes, of course, People with Disabilities (PWD), recognized as those who have long-term impairments such as a physical, mental, intellectual or sensory one, which, in interaction with one or more barriers, can obstruct their full and effective participation in society on equal terms with other people.<sup>1</sup> From a few years ago up to now, the country has had a specific policy aimed at health care for this demographic, considering their specificities, aiming at their inclusion, rehabilitation and prevention of disabilities with articulated actions, including access to assistive technologies such as orthoses and prosthetics, among others.<sup>2</sup>

Worldwide, it is estimated that 15% of the population has some type of disability. In Brazil, data shows that more than 12 million people have a disability, which may be present from birth, with most of them appearing throughout life, especially in old age. Disabilities can be of different types, such as physical, visual, intellectual, auditory, and Autism Spectrum Disorder. Visual impairment is the most prevalent (3.6%), and hearing impairment is considered the one that most hinders people's participation in social life.<sup>3</sup>

Hearing impairment refers to situations of partial or total loss of sound hearing possibilities, which can fluctuate in degrees and levels. Individuals who have total or partial loss, whether congenital or acquired, in the ability to understand speech through the ear are called deaf.<sup>4</sup> Those who have reduced hearing or normal hearing in just one ear are not considered hearing impaired.

Brazilian legislation recognizes the Língua Brasileira de Sinais - Libras (Brazilian Sign Language) as a legal means of communication and expression with these people. The legislation points out that institutionalized ways of supporting the use and dissemination of this as a means of communication with the deaf community must be guaranteed by the public authorities. It also describes that public health services must guarantee adequate care and treatment for people with hearing impairments.<sup>4</sup> There are also other ways of communicating with people with hearing impairment, such as lip reading, although it presents limitations for understanding.

Despite the advances made in favor of PWD, provided for in the Brazilian Law on the inclusion of people with disabilities, also known as the Estatuto da Pessoa com Deficiência (Statute of Persons with Disabilities), it is observed in the daily life of health institutions, in different levels of care, that healthcare professionals, in general, have difficulties dealing with these people, especially those with hearing loss. In these services, the nursing team is the most numerous professional category, and they work directly with patients in health promotion, prevention, assistance and rehabilitative actions, and it is essential that they can communicate with the population assisted so that it is possible to provide care effectively and safely.

Literary texts highlight the weaknesses of these professionals when interacting with deaf patients. In a survey carried out on the communication of the nursing team with people with hearing impairment in a teaching hospital, with 44 professionals from the nursing team, it was found that they did not know sign language (Libras) and resorted to lip reading, miming, writing and intermediation with companions to try to communicate with these people.<sup>5</sup> In another study, done with 60 nursing professionals, in addition to the lack of knowledge of Libras, the lack of complementary materials and the unavailability of interpreters in hospitals were highlighted.<sup>6</sup>

It is known that undergraduate courses that contemplate the singularities of interaction with these people are rare. Libras courses, when offered by higher education institutions, are almost always an optional subject, so learning is not guaranteed for all future professionals, except for professionals in the areas of pedagogy and speech therapy. Literary texts were scarce regarding health care aimed at this population, especially based on 'listening' to these people about their needs and expectations when looking for services.

In an integrative review carried out, which had as its guiding question the potentialities and limitations of the communication process for deaf people in health services in Brazil, nine studies were found. Among those who presented considerations on the part of people with hearing impairment, there was a feeling of anguish, exclusion, and disrespect regarding their needs, as well as expressing doubts and fears that misinterpretations would put them at risk.<sup>7</sup> These are data that indicate that these people are not being adequately assisted by health services.

The philosophy of patient-centered care is recent in Brazil and has been gaining more and more importance in health institutions. It involves listening to and meeting the needs of patients, considering their values, objectives and preferences, in a personalized and humanized way, with decision making together with them. In this context, the patient's experience becomes important, with their reports, complaints and demands, through which it is possible to observe the main sources of satisfaction and expectations regarding those services. The more positive the care experiences in health services, the more engaged in self-care patients will be, contributing to achieving good health as a whole.<sup>8-10</sup>

The making of this study is justified by the need to rethink health care aimed at this population, considering the singularities of these people, hoping that the results can contribute to advances in health care aimed at this population, which has historically lived on the margins of society.

Considering this context, this study aimed to discuss health care of people with hearing impairment, based on the experience of a user.

## 2. Method

This is a case report whose data comes from everyday practice. The report was made by a deaf person, with a high level of education, who, as a speaker at a university extension event, presented his experience in using health services. She gave the explanation in Libras, which was translated by an interpreter. At the end of her presentation, given the richness of her report and the importance of the content explained, she was invited by a nurse researcher and activist on the topic of social inclusion and with experience in carrying out qualitative research to present her experiences in written form, so that they could be shared through a scientific study. She promptly expressed her acceptance, with satisfaction, and then the participant and researcher began to communicate by email.

The researcher sent, together with the free and informed consent form, a script with open questions that could guide the writing of experiences in health services, covering everything from the moment of diagnosis of hearing loss, through the experience of living with it, and about the care received in health services. The participant was informed about its risks and benefits, and about the guarantee of anonymity of the information, as well as the right to refuse without any prejudice, following the recommendations of Resolution 466/12.

The analysis of the narrative was comprehensive, based on the theory of Structural Analysis of Narration, which considers the interview as a process of reflection by the subject on the topics covered, which leads to a reconstruction of their own ways of interpreting them.<sup>11</sup> The findings were discussed considering current legislation in Brazil, relevant literature, and the theoretical framework of patient-centered care.<sup>8-10</sup> The study in this report was approved by the Research Ethics Committee, CAAE number 32557420.0.0000.5149.

## 3. Results

In order to guarantee the anonymity of the participant, data that could lead to her identification were omitted, only those essential to the contextualization of the speech being presented. The participant is female, aged between 30 and 40 years old, and was doing postgraduate studies, which, according to her, is something rare among people with hearing impairment. The narrative resulted in the construction of two thematic categories: the experience with hearing impairment, and the perception about the care provided in health services to people with hearing impairment.

### 3.1 Living with hearing loss

The interviewee stated that she had a genetic hearing loss, but that it was not of high degree from the beginning, and that her educational training was affected by the delay in detecting the deficiency:

*"I ended up being harmed at school, as the hearing loss existed, but the recognition that I was deaf did not exist for me, nor for my family, much less for my teachers who never realized, not even at a time when dictation was one of the main tools for teaching Portuguese. And as the hearing loss existed, I ended up having to repeat basic education five times. That's right, I flunked out five times. Each year passed I lost a little bit of my hearing. Today it is considered to be of high degree, different from the diagnosis 10 years ago, in which it was moderate to severe. But I only discovered my disability when I was 11."*

She stated that her grandmother and mother have hearing impairments, and among the eight uncles she has, only two do not have hearing problems, with the others having a high degree of hearing loss. She said that her son hears normally, and that his current partner also has hearing loss.

When asked about what it was like for her to have a hearing loss throughout her life, she reported the difficulties she encountered, including accepting herself:

*"As I grew up in the countryside, it was difficult! The city had no structure for anything. There were no trained professionals, and because it was a small city, there weren't that many deaf people, or if there were, I didn't get to know them. It was difficult to accept my disability, especially in my adolescence. I even tried against my own life by not accepting it. I only accepted my disability and identified myself as deaf when I started to have contact with other deaf people and with Libras. I learned Libras late, at 23 years old. From that moment on, everything became easier, more acceptable, more normal, after all I'm just deaf, I'm not an alien (laughs)".*

It is observed in the excerpt above how the experience of disability at that time impacted the participant's self-esteem, causing an attempt at suicide during adolescence. The report also shows how living with other deaf people and learning sign language contributed to accepting the limitation, as well as overcoming it.

When asked about how she learned Libras, she said it was triggered by the work achieved, in which there were other hearing-impaired people who used sign language:

*"When I was approximately 23 years old, I was called to work. I was very happy, as I really needed to work during that period. I was recommended for a job at a public company. When I got there, I came across more than 20 deaf people, all signing. I was the only one who didn't sign. I was rejected a lot by them, and with a lot of patience, I tried to get closer, and every day I learned something from them. As my position was typist, we were entitled to a 10-minute break. During this period, I was absorbing Libras. I learned about the vision of the deaf community, received my sign (I was baptized), fell in love with it, and loved Libras and accepted it as my language. In less than 6 months I was already fluent and communicating clearly with my coworkers."*

This statement highlights the benefits that learning Libras brought to the interviewee's social life, as well as to her work activities.

She reported having used a hearing aid, however, without success. She pointed out that the cochlear implant does not solve 100% of cases, and made a social criticism of the fact that hearing impaired people are not socially accepted as they are, there being always a search for a 'cure' for them:

*"Everything was magnified, except people's voices. My head hurt like hell, not to mention the stress. Out of 100 people, 1 or 2 are successful. I know more people who have not had success with hearing aid than who have had success. But why does society try to normalize us deaf people? Why don't you accept us the way we are?"*

### **3.2 The perception regarding the care provided in health services to deaf people**

When discussing health care, the participant's speech highlighted difficult aspects, such as the lack of preparation of health professionals to deal with deaf people. She also expressed that professionals are more focused on quantity of care, paying little attention to the quality of care provided.

*"The biggest difficulty is the lack of prepared professionals. Law 10436/2002 guarantees us access to healthcare, but, unfortunately, this does not exist in practice. Nowadays, professionals are more concerned with caring for many patients than providing quality care. Today everything is viral, unfortunately! Many deaf people, like me, end up self-medicating, because we often don't even understand what the professionals are saying."*

It can be seen from the excerpt above that communication does not occur effectively, as it appears not to be understood by the recipient of the message, which ends up leaving them vulnerable and at real risk.

When asked about the scope of health promotion actions in the hearing-impaired population, the participant points out that they do not achieve the final objective in this group and are even misinterpreted. The result of this ineffective communication is that they remain uninformed, with chances of seeking clarification through the use of social networks among them, since some of them are able to understand and translate the information to the others:

*"Of course deaf people don't understand promotion and prevention actions! Often the information is even interpreted differently by them. Guys, this is serious! Deaf people don't know what HPV is! I, for example, only know that it is a disease, but whether it is contagious, or caught through sex, or from mosquitoes, I don't know. Now we know about dengue because among us deaf people there is a person who read it, understood it completely and ended up signaling it and playing it on social media. The media invested in these campaigns by the government does not reach the deaf".*

When reporting her experiences of care in health services, her speech illustrates many difficulties in meeting her needs:

*"My son had an allergic reaction to Benzathine penicillin. He was sent to the ICU (intensive care unit). Think of a desperate mother: that was me!. Well, his father stayed with him most of the time, I was only in the hospital for one day. And I felt so useless there! The nurses who entered the room had no patience, they didn't know how to talk, not to mention that I slept without a sheet because I needed to call to ask for it, but how could I call? I went to the nurses' station and asked them to request the sheet, and I didn't even need to draw the "goodwill" face of the nurse who was on duty! When the day dawned, my son's father arrived and was already talking to doctors and nurses, and I had to wait for him to tell me my son's diagnosis. Think about how I felt!"*

In this report, the deponent expresses her suffering and feeling of indignation at not having been informed about her hospitalized son's diagnosis. Her speech signals the lack of individuality in the care provided to a mother who had a child in a critical condition, as well as the lack of humanization, since no alternative was sought to overcome the communication problem.

The interviewee wanted to report two situations experienced by deaf friends in health services, reinforcing the weaknesses of care for deaf people:

*"I have a couple of friends, the wife is hearing and the husband is deaf. They went to the ophthalmologist and as it was taking a while, the wife went downstairs to smoke. My deaf friend was waiting. They ended up calling him and his wife wasn't around, but she could hear the doctor practically shouting at him, and the secretaries giggling. Immediately the wife went upstairs, entered the doctor's room and asked him to speak quietly, that there was no point in shouting at her husband, saying that he was deaf, and that he just had to gesture calmly. Imagine the embarrassment. Such an ugly attitude from these professionals."*

This report illustrates inappropriate conduct by health professionals, highlighting their lack of preparation, as well as disrespectful conduct that causes suffering and exclusion.

She also expressed another experience of deaf friends:

*"I have also a friend for years who is deaf and so is her husband. They had 3 children. During the week the children stay with their maternal grandmother. She is the one who takes the children to health services, provides monitoring and other things, due to difficulties in communication. My deaf friend told me that doesn't make her any less of a mother. She said that when her son gets sick, she gets nervous because she doesn't understand what her son actually has. Very sad!"*

In this example, implications arising from communication difficulties are observed, even affecting the performance of the maternal role, causing more suffering.

The deponent concluded her speech by reinforcing the importance of quality interaction with deaf people in health services:



*“Life is a rush for everything. Sometimes, in this rush, we forget to always do our best, as we are focused on doing more. But more is not always right. When you come across a deaf person, look into their eyes! Try to communicate with them in as many ways as possible! Try to show them that you are willing to help! Don't be an arrogant professional. Do not use a mask (referring to a mask used as personal protective equipment) when communicating, as it makes communication difficult. Best of all: learn Libras and make a difference! If you are giving medicine to a deaf person, explain what the medicine is for, how long it will take to take effect, and come back and ask if everything is ok. Sometimes they wish to say something. Healthcare professionals need to always do their best. After all, we deaf people need you.”*

She concluded by asking them to be 'listened to', to be made an effort, to show interest, to be empathetic, and to be careful not to wear masks given the use of lip reading by many people with hearing impairments.

#### 4. Discussion

This experience report, made by a person with hearing impairment and a high education degree who is very enlightened about their rights and with a keen critical sense, provides valuable information to reflect on the health care offered to this population, and plan actions for improvements in health services.

The fact that the participant is a postgraduate student indicates that many obstacles were overcome by her, based on data from the 2023 Census carried out by the Instituto Brasileiro de Geografia e Estatística - IBGE (Brazilian Institute of Geography and Statistics). They showed that, in the general population, 4.1% are illiterate, with this percentage rising to 19.5% among PWD. While 20% of the general population has a higher education degree, only 7% of PWD reach this level of education. No specific data was found on deaf people, but it is believed that this type of disability represents an important obstacle to reaching higher education, especially when the PWD does not use Libras. And the difficulties in professional training end up reflecting on the employability of this group, with only 26.6% of them being employed, as shown in the census, with implications for other spheres of life, such as income and quality of life, among others.<sup>12</sup>

The reported experience of health services usage was marked by dissatisfaction resulting from important failures, ranging from the treatment received in the services, which was inadequate and sometimes disrespectful, such as the failure to meet their needs. The report denounces the lack of interest and effort on the part of the health professionals in finding ways to try to relate to this public and overcome communication barriers. This situation leaves both parties without essential information, making it impossible to provide qualified assistance.

Difficulties in communicating with hearing impaired people have been known for a long time and have been identified in previous studies, which allows us to state that few advances have occurred in this sphere, despite the numerous technological advances achieved in recent years.<sup>2-4</sup> This situation leads us to a lack of interest on the part of professionals and managers in changing it, or to conformism and even ableism, which considers this reality as something normal.

Communication is an essential instrument for human interaction and development, and when not made viable, it causes numerous negative impacts, including not learning self-care in health, essential to life. Therefore, alternatives to remedy this barrier need to be implemented quickly in health services, as it is essential for the inclusion of these people in these spaces. The use of writing is highlighted as an important and very accessible communication resource with this population, which could even be done through messaging applications, such as WhatsApp. However, it is necessary to carefully analyze the linked content and its understanding by users, since the level of education among them can be quite varied. Educational videos with subtitles could also be shared, taking the same precautions to assess understanding.

Considering that lip reading is still the most used resource in interacting with people with hearing impairment, it is necessary to train professionals on its use, to avoid mistakes. In this case, the professional must face the person with hearing impairment and speak calmly, using words that are easy to understand, with good articulation. You must also use facial and body expression to demonstrate

feelings, since the deaf person does not perceive changes in the intonation of their voice. It must be expressive, and if you have difficulty understanding what the deaf person said, ask them to write it down. It is also necessary to ensure that the environment is clear and well lit, ensuring good visibility. And if the deaf person is with an interpreter, be careful to address them, and not the interpreter.

In situations where patients communicate using Libras, institutions need to provide translators when there are no professionals capable of using the language. They must also promote and/or value learning Libras for members of their care team, just as they value specialization.

Furthermore, professionals need to be encouraged to reflect on existing prejudices and encouraged to act to ensure accessibility and inclusion of PWD in health services. They need to be sensitized to welcome these people when they seek services, establishing a bond and coordinating a continuous and comprehensive care, covering all the needs of PWD, including those of a psycho-emotional nature.

The patient's report gives concrete examples that the care provided does not take place with the patient in consideration, since people with hearing impairment are not considered 'people' who participate in health actions, and their values and preferences are not considered, since they are not even heard. The experience report, which is believed to be representative of many other services carried out with people with acusia, shows the need to innovate the way care is provided so that it is centered on people, based on the identification of their objectives and preferences, in an individualized and humanized manner.<sup>5-6</sup> We cannot lose sight of the fact that users are the reason the services exist, and it is based on their needs and for them that they must be organized.

It is important to point out that patient safety is now a premise in healthcare throughout the world, widely disseminated by the World Health Organization, and effective communication between the healthcare team and patient is one of the goals to achieve this premise.<sup>13</sup> At the same time, ensuring accessibility and social inclusion of PWD is an aspect to be treated as a priority by health institutions, as they involve human rights, and are an ethical and humanitarian responsibility expected of all managers.<sup>1-3,5,6</sup>

It is also worth remembering that the prevalence of hearing problems tends to increase, considering the aging of the population, which reinforces the urgency of training professionals not only about how to interact with them, but also how to prevent damage caused by this type of disability. Studies show a tendency for people with hearing impairment to be socially isolated, which can cause other damage, such as depression. It is also appropriate to highlight the need to reinforce preventive actions for the occurrence of hearing loss, from pregnancy, childbirth and postpartum and throughout life, considering the different factors related to its occurrence. It is essential that early diagnosis of hearing loss is made, aiming to direct appropriate treatment, mitigating damage.<sup>14-16</sup>

It is hoped that this report will contribute to making professionals look for ways to resolve existing barriers in communicating with people with hearing loss, who so much need and deserve qualified and effective care.

The limitations of this study are the fact that it is the report of just one person. However, given the difficulty in carrying out studies with these people at the expense of the difficulty of locating and contacting them, and also considering that the participant had a high level of education, it was decided to take advantage of the potential that her report could bring for all people with hearing loss, and for health services.

## 5. Conclusion

This report of experiences by a person with high degree hearing loss in health care shows that institutions and health professionals need to overcome barriers and innovate in meeting the needs of this public quickly, since they are in a situation of greater vulnerability arising from barriers in communication.

'Listening' to specific and historically excluded audiences - such as deaf people - is essential for advances in the provision of assistance, for they are capable of providing valuable information that is impossible to achieve in other ways, since there are aspects that only those who experience it in their own skin could know. And what is expected is that experiences using services are positive, effective and

satisfactory, and not marked by disrespect, anguish, fear, suffering and exclusion, as it seems to be for these people.

Health institutions need to invest in training professionals. Higher education institutions also need to review their curricular structures and ensure the teaching of Libras to a greater number of students, and not in such a limited way, as is currently the case. Promoting inclusion must be a goal for everyone, so that people with disabilities can also enjoy a dignified life.

### Conflicts of interest

No financial, legal, or political conflicts involving third parties (government, private companies and foundations, etc.) have been declared for any aspect of the submitted work (including but not limited to grants and funding, advisory board membership, study design, manuscript preparation, statistical analysis, etc.).

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