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Perception of deaf patients about medical care

Percepção de pacientes surdos acerca do atendimento médico

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ABSTRACT

Deaf people are those who understand and interact with the world through visual language. Due to the linguistic and cultural differences that characterize the deaf population, this group still faces difficulties in accessing health services. For this reason, it was proposed to investigate communication difficulties in providing care to deaf patients. This is a qualitative study which was carried out at the Association of the Deaf of Maranhão (ASMA), in São Luís. The sample consisted of ten women and ten men, all over the age of 18. The information was collected through semi-structured interviews, with the help of Brazilian Sign Language (LIBRAS) interpreters. Data interpretation were performed based on thematic content analysis. Two thematic categories were identified: "Communication" and "Autonomy". In the first, the interviewees pointed out the lack of knowledge of the doctors about the needs of the deaf community or about their language, LIBRAS. In an attempt to establish a dialogue, the patients reported the use of writing, gestures and orofacial reading during the consultations. These strategies, however, are insufficient, since the information cannot be well understood. The second evidenced the need for the presence of companions to mediate the dialogue, as the participants stated that they did not find LIBRAS interpreters in the health units, resulting in loss of autonomy and confidentiality of information. It is concluded that this scenario of adversity implies important consequences for the health of this population, as well as lower adherence to treatments and a decrease in the search for medical care.

Keywords: Communication Barriers. Health Services Accessibility. Medical Care. People with Hearing Impairment.

RESUMO

O sujeito surdo é aquele que compreende e interage com o mundo por meio de linguagem visual. Devido às diferenças linguísticas e culturais que caracterizam a população surda, este grupo ainda enfrenta dificuldades no acesso aos serviços de saúde. Por essa razão, propôs-se investigar dificuldades de comunicação na prestação de cuidados a pacientes surdos. Trata-se de um estudo qualitativo, que foi realizado na Associação de Surdos do Maranhão (ASMA), em São Luís. A amostra foi constituída por dez mulheres e dez homens, todos maiores de 18 anos. As informações foram coletadas por meio de entrevista semiestruturada, com o auxílio de intérpretes de Língua Brasileira de Sinais (LIBRAS). A interpretação dos dados foi realizada a partir da análise temática de conteúdo. Foram identificadas duas categorias temáticas: "Comunicação" e "Autonomia". Na primeira, os entrevistados pontuaram o desconhecimento dos médicos sobre as necessidades da comunidade surda ou sobre sua língua. Como tentativa de estabelecer um diálogo, os pacientes relataram a utilização de escrita, de gestos e de leitura orofacial durante os atendimentos. Essas estratégias, contudo, são insuficientes, visto que as informações não conseguem ser bem compreendidas. Já a segunda evidenciou a necessidade da presença de acompanhantes que intermedeiem o diálogo, pois os participantes afirmaram não encontrar intérpretes de LIBRAS nas unidades de saúde, acarretando perda da autonomia e da confidencialidade das informações. Conclui-se que esse cenário de adversidades implica consequências importantes na saúde dessa população, bem como menor adesão a tratamentos e diminuição na busca por atendimento médico.

Palavras-chave: Acessibilidade aos Serviços de Saúde. Assistência Médica. Barreiras de Comunicação. Pessoas com Deficiência Auditiva.

INTRODUCTION

As it covers the entire Brazilian population, the Unified Health System (SUS) must be able to serve the community with disabilities, with the same quality of service provided to people without disabilities (Gomes et al., 2017). However, deaf individuals continue to have relevant difficulties in accessing health; mainly due to communication barriers (Kuenburg, Fellinger & Fellinger, 2016).

According to Decree No. 5,626, of December 22, 2005, hearing loss is considered to be bilateral hearing loss, total or partial, of 40 decibels (dB) or more, at frequencies of 500, 1,000, 2,000 and 3,000 Hz, measured by audiogram (Brasil, 2005). Hearing loss can also be classified according to the mean of the frequency thresholds described as mild (from 20 to 35 dB), moderate (from 35 to 50 dB), moderately severe (from 50 to 65 dB), severe (from 65 to 80 dB), profound (from 80 to 95 dB) or complete hearing loss/deafness (above 95 dB) (Conselho Federal de Fonoaudiologia, 2020).

From the sociocultural point of view, deaf people are those who understand and interact with the world through visual experiences, manifesting their culture, mainly, through the use of the Brazilian Sign Language (LIBRAS) (Brasil, 2005; Citton, Santos & Arossi, 2021). Thus, there is an understanding of deafness as a linguistic and cultural difference represented by LIBRAS as a first language, giving the deaf the concepts of identity, culture and their own language, who do not see themselves as individuals marked by loss, but rather as members of a linguistic and cultural minority (Strobel, 2008; Guimarães, 2014).

According to data from the 2010 Demographic Census of the Brazilian Institute of Geography and Statistics (IBGE), Brazil has approximately 9.7 million people with hearing loss, of which 349,618 live in the state of Maranhão (IBGE, 2010). These numbers highlight the fact that we live in a society that is mostly hearing, so verbalized communication, especially oral/auditory, is a key element in interpersonal relationships, since individuals interact through it. In this regard, it is emphasized that, in the health area, it is essential to establish a professional-patient relationship with quality and adequate care (Karsten, Vianna & Silva, 2017).

In this sense, hearing loss, therefore, can have an impact on the development of communication and socialization, as expressed by Dutra, Cavalcanti & Ferreira (2022). Deafness, however, is not the limiting factor, but rather the inaccessibility to a language. Thus, this lack can lead to loneliness and compromise the development of mental capacities (Gesser, 2009).

Due to communication barriers, the deaf population has significantly fewer opportunities for access to adequate information on prevention, treatment, and health care, which is provided in an insufficient manner and without any depth of content (Oliveira, Celino, França, Pagliuca & Costa, 2015). This occurs because of the scarcity of accessible systems that take into account the particularities of deaf patients, leaving them in a situation of social vulnerability, once the lack of knowledge of the LIBRAS language on the part of physicians and the lack of interpreters at health units arouse negative feelings and discourage deaf people from seeking health services, because of the fear of not being understood (Santos & Portes, 2019; Pereira, Passarin, Nishida & Garcez, 2020).

The Brazilian Law No. 10,436, of April 24, 2002, known as the “LIBRAS Law”, ensures the adequate provision of care to deaf people by public institutions and companies that concession public health care services (Brasil, 2002). In a study conducted by Gomes et al. (2017), in which 101 physicians from the Brazilian public health system in the Federal District were interviewed, it was found, however, that 92.1% of the participants stated that they had received deaf people, but only one of them declared to have basic knowledge of LIBRAS. Thus, there was a predominance of the feeling of discomfort during the consultations, which demonstrated the lack of preparation of the physicians to interact with these patients.

Considering the scenario of difficulties, the deaf community has fewer medical consultations than hearing individuals and there is a greater probability of avoiding health professionals as a result of the lack of communication and the absence of a LIBRAS translator/interpreter, as Laur (2018) points out. This demonstrates the social neglect suffered by this population that has specific communication needs (Schniedewind, Lindsay & Snow, 2021).

For this reason, this theme little addressed in the literature motivated the present work. Thus, it instigated to investigate the problems and communication barriers that can interfere in the provision of health services to the deaf population.

MATERIALS AND METHODS

An observational, descriptive, qualitative and cross-sectional study was carried out on the premises of the Association of the Deaf of Maranhão (ASMA). This association was founded on January 12, 1979 in the city of São Luís, state of Maranhão, Brazil, and promotes activities in defense of the social rights of the deaf population.

The sample was defined by the saturation criterion and consisted of 20 participants (ten men and ten women), corresponding to 20% of the total number of deaf people assisted by ASMA. The following inclusion criteria were used to take part in the study: deaf individuals who communicate using LIBRAS, lip-reading or both, aged 18 or over and who regularly attend ASMA. The following exclusion criteria were listed: not answering all the interview questions or not taking part in the interview. Once the criteria had been specified, all participants signed the Informed Consent Form (ICF).

The information was collected through a semi-structured interview consisting of 15 guiding questions. The questions were prepared by the authors and asked about the establishment of adequate communication and the quality of medical care (Table 1).

The interviews were carried out in a private room at ASMA, from August to November 2021, with the help of LIBRAS translators/interpreters, who voluntarily contributed to the study. The language mediation professionals translated the participants' answers into Portuguese and the oralized translation was recorded on an audio device. These audios were then transcribed for subsequent analysis and used only for this study. In order to ensure that the identity of the participants was protected, their anonymity was maintained. During the course of the research, when mentioned, the participants were identified with the letter E, followed by numbers in the ascending order of the interviews.

Data interpretation involved thematic content analysis (Godoy, 1995). The interview transcripts were read repeatedly and the answers were grouped into categories common to the themes addressed. The categories were reorganized into subcategories. Finally, subcategories with significant content for the objective in question were identified.

This study was approved by the Human Research Ethics Committee of the hospital affiliated to the Federal University of Maranhão (approval no. 4.648.961; submission number: 44219521.0.0000.5086).

RESULTS AND DISCUSSION

The study sample consisted of ten men and ten women, aged between 18 and 62 years, who communicated through LIBRAS. Of this sample, half also used lip reading. Two thematic categories were identified: “communication” and “autonomy”.

Within these categories, ten subcategories were grouped. For better analysis, the category “communication” was divided into “Forms of communication during medical consultations” and “Communication barriers between deaf patients and doctors”. The ten subcategories that make up the two categories were eight in the “communication” category: “Writing”, “Intermediation of family members”, “Lip reading”, “Gestures”, “Illegibility”, “Jargon”, “Lack of knowledge of LIBRAS” and “Absence of interpreters”. In the “autonomy” category, there were two: “Dependence on companions” and “Passivity in the health-disease process”. The Tables show the categories and frequency of each subcategory.

In Table 2, the interviewees reported different forms of communication that they use during medical consultations. The feeling of dissatisfaction, however, was evident, as the participants declared, in the different subcategories, that the information could not be adequately transmitted.

Table 3 shows the main communication barriers, highlighting the “lack of knowledge of LIBRAS” and the “absence of translators/interpreters”, mentioned by “E18” and “E19”, respectively, of the 20 participants. These reports show that the health system in the city of São Luís does not offer accessibility to the deaf community, as doctors do not know sign language and are unable to establish effective communication with deaf patients. Participants also do not have access to LIBRAS translators/interpreters in health units. Reports such as that of “E5” emphasize that communication barriers can cause traumatic experiences for these patients. It can be inferred, therefore, that the health system, which should be responsible for welcoming the individuals who seek it, leaves the deaf community in a situation of vulnerability and exclusion.

Table 4 shows that deaf patients lose autonomy over their own health situation. This is due to the fear of being misunderstood or the apprehension that something bad might happen due to the difficulties generated by the lack of communication. This contributes to deaf people relying on other people to access health services. Moreover, the companions are also unable to completely mediate the dialogue, because they do not have extensive knowledge of LIBRAS, making the deaf oblivious to information about their own health.

Table 1
Semi-structured guiding questions.

The establishment of adequate communication:	The quality of medical care:
1) What are the main problems you identify when a deaf person searches for medical care?	1) What do you think about the communication between deaf patients and listening physicians?
2) Have you ever received medical assistance in LIBRAS?	2) Do you think doctors are prepared to assist deaf people?
3) What forms of communication have you received from a doctor?	3) Do you feel like you lack privacy when you need someone to mediate the communication with a doctor?
4) Is it easy for you to understand medical advice through lip reading?	4) What would you feel if a doctor attended you in LIBRAS?
5) Is it easy for you to understand medical advice through written Portuguese?	
6) Is it easy for you to understand medical advice when the doctor makes gestures?	
7) Do you need to be with someone else to mediate the communication with a doctor? Who is usually the mediator?	
8) Have you ever had interpreters during a medical appointment? How was the experience?	
9) Can the interpreter or another mediator explain properly your feelings to the doctor or the medical recommendations to you?	
10) Do you follow the medical recommendation or prescription if there is no one mediating the conversation?	
11) Do you follow the medical recommendation or prescription if there is someone mediating the conversation even if you don´t understand directly what the doctor says?	

Source: The authors.

Table 2
Forms of communication during medical appointments.

Subcategory	Transcription
Writing (N = 15)	"It is always through writing. I also don't know much about the Portuguese language, but I am trying. Sometimes, he understands, sometimes, I don't understand." (E20) "Everything takes place by written communication. Sometimes, I don't know the words used by the doctor and it makes understanding more difficult." (E1)
Intermediation by a family member (N = 16)	"The doctors don't know how to communicate in LIBRAS. I have to go with my mother. I always have to be with another person to report what I am feeling." (E1) "The doctor didn't speak to me, he spoke directly with my mother. It seemed like she was the patient." (E20)
Lip reading (N = 4)	"When there is no understanding through writing, the doctor takes off his mask and I attempt lip reading." (E15)
Gestures (N = 9)	"We make gestures, facilitating signs, such as placing our hand on our heart." (E12)

Source: The authors.
Note. N = number of participants who mentioned the subcategory.

Communication barriers between health professionals and deaf individuals hamper comprehensive and qualified care. According to the participants, this is due to the lack of knowledge of health professionals in relation to the deaf community. Studies that have addressed the knowledge of LIBRAS by medical students point to the unfavorable academic curriculum in terms of training for the care of deaf patients as one of the factors of this problem (Oliveira, Oliveira, Jesus, Quintanilha & Avena, 2022; Silva et al., 2023).

The interviews revealed that this results in negative consequences, as deaf people are more prone to lack of adherence to treatment because they do not receive adequate information about their health conditions. Thus, the lack of preparation of physicians to care for the deaf community weakens the communicative bond, making these patients feel insecure during medical consultations, as well as in relation to the diagnosis and proposed treatment (Pereira et al., 2020; Santos, Magalhães, Uchôa, Freitas & Nascimento, 2022).

In order to minimize the undesirable consequences of a lack of effective communication, the participants reported strategies for trying to understand information during consultations through writing, gestures or lip-reading. These options, however, are often insufficient and medical advice is not fully understood, or is conveyed inadequately.

Table 3
Communication barriers between the deaf patient and the physician.

Subcategory	Transcription
Illegibility (N = 3)	"The doctor usually writes in a way that I can't understand." (E5)
Jargon (N = 6)	"Sometimes, he writes things that I don't understand, some technical terms that I don't know; so sometimes it is not accessible." (E10) "Many use very technical terms. I think that they could adapt the language so that I could understand it." (E14)
Lack of knowledge of LIBRAS (N = 18)	"Most doctors don't know how to communicate, but if they knew at least the basics, they would certainly be able to conduct the consultation. Communication would be much easier. So, if I feel any pain, any symptoms, how will he understand? It's important to know sign language." (E15) "I remember that, when I was pregnant, the person didn't understand me, I couldn't communicate and I almost lost my child. At the end, I had a caesarean section and wanted a normal birth. No one could go into the delivery room with me and no one knew how to communicate with me. I never want to have another child, it was too traumatic." (E5)
Absence of interpreters (N = 19)	"I could never count on the help of interpreters in the health units. I also never looked for an interpreter on my own due to the financial cost." (E19) "There are never any interpreters to help, it always has to be a family member, but it's complicated. I have to adapt the signs so that they understand me." (E6)

Source: The authors.
Note. N = number of participants who mentioned the subcategory.

Table 4
Autonomy of deaf patients.

Subcategory	Transcription
Dependence on accompaniers (N = 17)	"I only have one child and I can only go to the doctor if he goes with me, because the doctor doesn't know LIBRAS and if I go alone, I won't be able to communicate. If I die, if something happens, if I'm harmed? I'm afraid of that. That's why I always ask my son to accompany me, because he'll talk to the doctor and he'll understand. He explains that I am deaf and says everything I am feeling. But if I go alone, the doctor won't understand me. They only communicate verbally and deaf people are left alone, nothing is transmitted to us. It's not easy, in fact, it's quite complicated." (E3)
Passivity in the health-illness process (N = 14)	"It would be great if the doctor knew sign language, but that never happens. Sometimes, I even avoid taking the medications that the doctor prescribes for me, because I don't know if they will help or harm me. Sometimes, I don't pay attention to what the doctor tells me, I look for other ways to heal myself, I prefer natural things, such as teas. He only said that I have to take medicine for high blood pressure and didn't explain anything else. So, I don't take the medicine." (E7) "My family, who usually accompanies me, can't understand very well what I'm feeling. I want to gesture, but my own family doesn't know the language. So, they just give me medication and I use it." (E16)

Source: The authors.
Note. N = number of participants who mentioned the subcategory.

Another aspect highlighted was the importance of having a LIBRAS translator/interpreter as a linguistic mediator in the medical consultation. These professionals are responsible for promoting communication between individuals with hearing impairment and hearing people, contributing to the accessibility of deaf people in public services (Schniedewind et al., 2021). Despite knowing that this is a right guaranteed by law, 95% of the participants stated that they had not found LIBRAS translators/interpreters in medical consultations.

With the absence of translators/interpreters, deaf people are dependent on the availability of a family member or friend to access health services (Santos et al., 2022). Although the companions facilitate communication, the participants pointed out that, in most cases, they do not have comprehensive knowledge of LIBRAS, which makes it difficult to exchange information, causing deaf patients to feel distressed because they are not well understood.

In addition, there is the loss of autonomy and the right to confidentiality of information about one's own health, since the companions go from mediators to the main person in the conversation. This is because, according to the interviewees, doctors usually establish communication exclusively with their companions, leaving the deaf person unaware of the dialogue. In this sense, the communication barrier is the central and most significant factor with regard to deaf patients' access to health services (Vieira, Caniato & Yonemotu, 2017).

Based on the results of this study, it was inferred that deaf people face several obstacles in medical services. Participants showed discouragement with the way they are treated, often feeling sad, ignored and disrespected.

CONCLUSION

It is concluded that the deaf in the city of São Luís still face adversities in health services, mainly as a result of communication barriers. The difficulty of finding a translator/interpreter to help with communication during medical consultations, the lack of knowledge of physicians in relation to LIBRAS and the deaf community have a negative impact on the doctor-patient relationship. Another factor in this problem is the loss of autonomy of deaf patients due to the need for someone to mediate the consultation. This generates the dissatisfaction of these patients with the care offered and impacts on important consequences on adherence to the proposed treatments.

Compared to the other studies referenced in this study, the situation in other Brazilian cities is similar. Comprehensive and adequate care for the deaf is therefore an issue that needs to be studied so that this population can be guaranteed the accessibility that is guaranteed by law.

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CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

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The authors declare that they have no financial interests.

AUTHOR CONTRIBUTIONS

Conceptualization: I. C. S. *Data curation*: I. C. S., A. S. A. S., L. S. F. *Formal analysis*: I. C. S., A. S. A. S., L. S. F. *Investigation*: I. C. S., A. S. A. S., L. S. F. *Methodology*: I. C. S., A. S. A. S. *Project administration*: J. O. B. *Resources*: I. C. S. *Supervision*: J. N. S., J. O. B. *Validation*: I. C. S., A. S. A. S. *Visualization*: I. C. S., A. S. A. S. *Writing the initial draft*: I. C. S. *Revision and editing of writing*: I. C. S., A. S. A. S., J. O. B.

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