

THE INFLUENCE OF HEALTH PROFESSIONALS ON THE CHOICE TO USE SIGN LANGUAGE

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ABSTRACT

Objective: to understand how the conduct of health professional's influences (or does not influence) parents and/or guardians in choosing the use of sign language after the diagnosis of deafness. Method: descriptive study of qualitative approach carried out with parents/guardians of deaf children and adolescents. Data were collected through interviews, conducted in October and November 2021 in the city of Maceió/AL - BR, data were analyzed according to Bardin. Results: sign language is not the first alternative suggested to parents as a form of communication with deaf children, since professionals prioritize the use of hearing aids and cochlear implant, although often its effectiveness is questioned. Conclusion: the study contributes to expand the literature on the theme, which is still scarce, making it possible to discuss the privileged role that the health professional must positively influence the lives of deaf individuals and their families.

DESCRIPTORS: Deafness; Sign Language; Health Personnel; Professional-Patient Relations.

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INTRODUCTION

Worldwide, more than 1.5 million people live with some degree of hearing loss, and it is estimated that by 2050 this number could reach 2.5 million¹. Deafness is the generic term used to describe people who have profound hearing loss, which implies very little or no hearing². Hearing is formed by a set of channels that carry sound to the inner ear. These waves are transformed into electrical stimuli and sent to the brain, which is responsible for recognizing what is heard³.

The deafness may be congenital or acquired, causing the reduction or inability to hear sounds normally³. It can also be classified into degrees: mild, which has a loss of 26 to 40 decibels; moderate, with loss of 41 to 55 decibels; moderate/severe, with loss of 56 to 70 decibels; severe, loss of 71 to 90 decibels; and profound, from 91 dBHL⁴. In the severe degree, lip-reading is important to improve the understanding of words since it is possible to hear only noises and intense voices. In profound deafness, the condition is more critical, making it impossible to understand speech and communication.

Often, mistakenly, the deaf are treated as hearing impaired, however, there are distinctions between the two. In Brazil, people with deafness are mostly those who use the Brazilian Sign Language (Libras), while the hearing impaired are those who adopt the oral Portuguese language and make use of resources such as individual sound amplification devices, cochlear implants, or prosthesis⁵.

Although deafness can be understood as a limitation, from the organic-biological point of view, the deaf understand it as a sociocultural and linguistic difference, not characterizing it as an "abnormality", but as a difference, with its own history and culture. From this perspective, therefore, deafness is an identity mark, not a limitation or loss⁶. Moreover, it is important to note that terms such as "deaf-mute" are considered stigmatizing and bring with them many prejudices, which is why people with reduced hearing capacity prefer to be recognized as deaf, since the word "disabled" is understood as pejorative.

Hearing is important in human communication, since the loss of this sense in children can cause several disorders, including speech, language, emotional, educational, and social development. Early diagnosis is urgent in hearing loss and must be done according to the 1,2,3 rule; that is, diagnosis must be concluded by the second month of the child's life, and intervention started after the third month⁷.

Faced with a diagnosis of deafness, the parents/guardians of the child may choose to use hearing aids, cochlear implant or use sign language. And like any language, libras has its own grammatical structure - syntax, morphology, semantics, phonology - providing the deaf with the ability to communicate, express ideas, formulate concepts, etc... The earlier the contact of a deaf child with sign language, the lower the risk of linguistic delays⁸.

After being given the diagnosis of deafness of a child, the health professional has a privileged position to promote health through health education, greatly influencing the next steps to be followed by the family. However, many professionals are still unaware of the importance of Libras and its ability in communication and development of the deaf person⁸.

Given the above, the present study has as a general objective to understand how the conduct of health professional's influences (or not) parents and/or guardians in the choice for the use of sign language after the diagnosis of deafness. We sought to answer the following research question: How the conduct of the health professional influences (or does not influence) the choice of parents and/or guardians for the use of sign language after the diagnosis of deafness of the child?

METHOD

This is a descriptive study with a qualitative approach, descriptive because it is characterized by a rich description, and its findings may be presented by means of excerpts of the participants' speeches, field notes, among others. And qualitative, because it seeks the understanding of specific complex phenomena, in depth, of a social and cultural nature, through descriptions, interpretations, and comparisons, without considering their numerical aspects in terms of mathematical and statistical rules⁹.

The participants of the study are parents/guardians of deaf children and adolescents assisted by the Bilingual Institute of Qualification and Reference in Deafness - (*Instituto Bilíngue de Qualificação e Referência em Surdez*) - IRES, unit of the unit of the Association of Friends and Parents of Special People - (*Associação dos Amigos e Pais de Pessoas Especiais*)- AAPPE, located in the city of Maceió/AL. To establish the determination of the participants, we used as inclusion criteria: Parents/guardians of deaf children and adolescents (who used Libras or were learning the language); over 18 years old; and users of the Portuguese language. As exclusion criteria, were excluded parents / guardians who perhaps only used Libras as a form of communication.

Data collection occurred through semi-structured interviews supported by a form. They were recorded with the consent of the participants and then transcribed for a more adequate analysis by the researchers. All interviews were conducted at IRES with the sanitary precautions that the pandemic moment required, which occurred between the months of October and November 2021.

The interviews were conducted by the researchers in a reserved room in the institution and lasted an average of 30 minutes, a period during which the children were concurrently being cared for by health professionals in another environment of the IRES. The semi-structured form contained objective sociodemographic questions, capable of tracing a profile of the participants, such as age, education, marital status, and address, while the other questions related to the object of the study were subjective, aiming to reach the magnitude of the phenomenon.

The number of participants was defined by the data saturation criterion, that is, when the sample was able to reflect in quantity and intensity the magnitude and complexity of the phenomenon¹¹, reaching saturation with a total of 15 participants.

The data were analyzed using the content analysis proposed by Bardin¹⁰ in the thematic modality. Thus, the interviews were transcribed and read, initially, in a floating form, and then, exhaustively. The central ideas were determined, and then grouped by similarity, making them nuclei of meaning. The interview clippings (the most relevant speeches of the participants) were distributed among the nuclei; these, after their respective descriptive syntheses, were regrouped into themes, thus constituting two thematic categories.

The research was approved by the Research Ethics Committee (CEP) of the Tiradentes University Center (UNIT) with approval opinion no. 5.023.285.

RESULTS

Fifteen participants were interviewed, all female, between 27 and 57 years old. Of these, 12 were mothers and three were responsible for the children/adolescents. Seven had an incomplete elementary school education, four had a complete high school education, three had an incomplete middle school education, and only one had a complete college education. Of these, two were married and the others had a stable union, residing in the

interior of the Capital and in the upscale neighborhoods of the city of Maceió/AL, with a low socioeconomic level. Based on the organization and interpretation of the material produced in the interviews with mothers and caretakers, it was observed that the trajectory followed by them usually follows a pattern, even when there is a late diagnosis. These issues were observed and thus formed two categories of analysis: the trajectory prior to the diagnosis and the communication challenges; health professionals' guidance after the diagnosis and the choice for Sign Language.

Category 1 - Pre-diagnosis trajectory and communication challenges

In this category, when talking about the trajectory that preceded the diagnosis of the individuals in question, it can be observed in the discourse of the 15 interviewees that most of the reports revolve around the difficulty of the diagnosis after birth.

She was diagnosed in the clinic by (...) who is a speech therapist and a psychologist that I don't remember the name. Then (...) told me through the exams that she was deaf. She was already about 6 years old (S2).

At the time she was diagnosed with 1 year and some months by Dr. (...) in (...) who is a speech therapist. There I was advised to take (...) for treatment with the speech therapist until she was about three years old. (S3)

He was diagnosed with 4 years, I had a complicated pregnancy, so he had difficulty walking, I thought it was due to this complication in pregnancy. I took him to the speech therapist, and she asked for a complement from the ENT to give the diagnosis. (S6)

He was diagnosed with 1 year and 4 months at (...). But before that I found out at home that he couldn't hear, I only confirmed at the (...) that it was really that. Through the Bera test the otolaryngologist found out (S7)

With 3 years of age in (...), as he was being followed up because he was autistic, the otolaryngologist did the follow-up and diagnosed (...).(S8)

On the other hand, despite the majority presenting a late diagnosis of deafness, it was clear in some reports, even if few, that there was professional guidance still in the maternity through the neonatal hearing screening (ear testing):

He was five months old when he was diagnosed. I believe that it was the phono during the little ear test. But it wasn't in the maternity, it was here at AAPPE (S1)

He had the final diagnosis when he was four or three years old, I don't remember very well, just looking at the exams. The ENT doctor was the one who discovered it. When we left the maternity hospital, they told me to do the BERA because Heitor had not passed the little ear test. (S4)

She already left straight from (...), which is the maternity, with the diagnosis of deafness by the little ear test.(S6)

Regarding the difficulty of acceptance on the part of the mother after the diagnosis, it was evident in the interviews that most of them found it hard to accept the reality of the child, especially when it comes to the lack of inclusion present in society:

It was very difficult at first, I got very upset and wondered why this situation. In my family there was no one deaf, this frustrated me a lot, in addition, there is the prejudice. (S1)

I had to come to terms with the situation and accept it. And this is what made it easier and motivated me to have this calmer relationship with him in the beginning. (S4)

I went through a very strong period of mourning and found myself in a delicate situation, I questioned myself a lot, I was very shaken. But all this was diminished from the moment I went to AAPPE and started to see other children with the same reality as him having a normal life and that in the future they can get a job and have a life like anyone else. (S5)

My daughter was so saddened by her daughter's diagnosis that she practically abandoned her daughter and gave her to me to raise, I was very concerned at the time, besides seeing the child's suffering in seeing professionals insist on her using braces, we knew she wouldn't hear anything. Thatonlyhurther(S6)

When it comes to communication between mothers and children and the barriers of this, after the diagnosis or during the investigation phase:

When I had the diagnosis of deafness of my daughter, I already knew the libras language, even so it was very difficult at first it seemed impossible, but it is not.(S2)

Today the relationship with communication has been difficult, I wonder what her doubts are, because she is growing up and is ashamed to talk to me about some issues, I feel she avoids contact with other people for being deaf. (S3)

I always had to do that little trick to be able to maintain communication, right? I would point to things, mime. As he is autistic it ends up being even more difficult to maintain communication. (S7)

It was very difficult to communicate from the beginning, but after a while I got used to his way of speaking. That was before he started using the hearing aid, right? After he started using the hearing aid, it became easier, and I ended up not looking for another way to communicate.(S8)

Category 2 - Guidelines of health professionals after diagnosis and the choice for Sign Language

In category two, in the face of the interviews analyzed it became evident that the guidance given by health professionals to family members after the diagnosis of deafness presents a default in the face of initial health care, considering the difficulty portrayed by professionals in the knowledge of Libras, and this is exposed in:

The doctor passed me all the guidelines and told me about the cochlear implant, that's when I took him to Recife to perform the procedure to implant, but in his case, it had no result and the implant stopped working. He also had facial paralysis, because of this I was afraid to do this process again. (S1)

The first phono that diagnosed it guided me to get the cochlear implant, told me what exams would be necessary and everything else. However, it didn't work out, she didn't adapt, and it was a big headache. The second speech therapist encouraged me to study libras and told me about all the benefits of the language and the advantages it would bring to my daughter, right? In one part it was good, because it was a new way of communication with my daughter. (S3)

The phono when he confirmed her deafness guided us to put that implant. But at the time the place that implanted it was on strike. So, on my own I sought Libras. I always encourage my husband to study because I am illiterate and have great difficulty learning. My biggest fear is dying and leaving her depending on people other than me, you know?(S6)

We observed, among the interviewees, alternatives to be used in addition to sign language as shown in the following statements:

He has already used the cochlear implant and the hearing aid, but we were not successful

in those options. What really saved us was sign language, although my dream was that my son would do that lipreading course offered by (...), but I find it difficult for him to adapt. (S1)

When I discovered deafness, I was urged to do surgery on him. But I never wanted to. He never used this device; our best alternative has always been Libras. (S2)

We even tried the use of hearing aids, but we had no luck, so today she is a student of Libras. If I had the knowledge that I have today I would have encouraged her to dedicate herself to the study of lipreading. (S3)

In the beginning he used a hearing aid, but due to an infection that he had in his ear he had to take a break for treatment. (S9)

It was notable in the statements above that options other than sign language were always suggested, such as hearing aids and cochlear implants, even in cases in which the child never used either of these two resources. It was evidenced, however, that the resource most used by the children of the participants interviewed was sign language, because the other methods ended up not being successful as mentioned in the interviews. One of the means that was also mentioned in some interviews was a lip-reading course, well known by people diagnosed with deafness and their families.

In view of the information obtained about the guidance given by health professionals to family members, the caregivers reported challenges that arose from the discovery to the present day:

I think this situation really messed with me; at the time I remember feeling guilty for the whole situation. But for sure my biggest challenge was finding a health professional that would give me a quick diagnosis. We were thrown from one professional to another and no one could conclude. It was very painful. (S2)

Our financial situation is not the best, the rush is great to get the exams he needs. Nothing comes easily when you don't have money, your hands are tied. It is a daily challenge to have to hold on and take care of everything (S4)

I live in another municipality; the interior is very far away. The commute is a challenge that makes us think about giving up. I am a civil servant and don't have much recourse. (S5)

I speak for myself, but I think all mothers went or still go through this situation. Our biggest challenge, for sure, is communication. Especially in the beginning. It hurts a lot to want to express yourself and not succeed, or to see the person you love trying to talk and failing. But love conquers everything and makes us move on (S8).

DISCUSSION

The family establishes the first form of communication with the deaf, therefore, the form of interpersonal communication and family communication will determine the subjective formation of the deaf and his level of communication and development⁵. In the family environment of deaf people, we prove the feeling of unpreparedness through the speech of the interviewees. Most families deal with deafness, but have little knowledge about sign language, so there is no greater interest in learning and using Libras with children and adolescents, which leads to the absence of a common language, thus contributing to a low quality of communication.

It was possible to observe that most of those responsible for the deaf children and adolescents are the mothers, who end up having the responsibility to take care of them and

deal with the problematic situation of communication, culminating in pressure and overload due to the lack of support. The unpreparedness of families in dealing with deafness produces an ineffective communication between parents and children, limiting the interactions within and outside the family environment, which compromises the development of social and intellectual skills¹².

The term “deaf” is vague and, at the same time, all-encompassing, because one must consider the varying degrees of deafness, which are of qualitative importance.

There are individuals who have difficulty hearing, who can hear part of what is being said with the help of a device, which is the hearing aid. There are also those who are severely deaf, who in some cases are victims of disease or damage to the ear in their youth, even though with the aid of the device it is possible to hear speech. There are also the profoundly deaf, which are the totally deaf, they are not able to talk in the usual way, they cannot hear any speech, no matter what technological advances are used, they need to use sign language¹³. In professional experience, it is perceived that the Neonatal Hearing Screening (NHS), has facilitated the diagnosis, although it has not been observed success among the interviewees of this study. Most children with congenital deafness referred by health professionals to specialized centers did not have a timely diagnosis.

It is worth noting that the earlier the hearing assessment, the earlier medical and educational interventions can be started before there is significant damage to the child. A late diagnosis can lead to developmental delays and often lead to a lack of understanding between hearing parents and deaf children¹⁴.

The birth of a child with hearing loss is a moment of destruction for the family, changing its previous balance and often generating a state of tension. Once the diagnosis is confirmed, parents go through a period of negative feelings, partially forgetting the child's other potentialities¹⁴.

In this study, it was observed that most respondents obtained a late diagnosis; most reported the discovery between four and six years of age of their minors. Deaf people often stop seeking health services due to the difficulty of communication with professionals in the area, in addition to the perception of prejudice by the health team and other users¹⁵. This distance between professionals and deaf people can directly affect the health status of these individuals, impacting the prevention of diseases and health promotion.

The relationship of health professionals with patients with normal hearing level is established by verbal contact. This mechanism is not often used by deaf patients who use sign language to communicate¹⁶. Among the interviewees of the present study, it was observed that most had a direction from professionals, mostly speech therapists, focused on the use of hearing aids and cochlear implantation, although in some cases the degree of deafness precluded the effectiveness of the options suggested.

In the interviews it was clear how lost those responsible are when they receive the diagnosis, since the first option suggested by health professionals is focused on alternatives that can bring consequences to the health of the deaf person from the simplest as pain in the ear to the most complex as facial paralysis. It is only when they arrive at rehabilitation institutions through a referral that they receive from the speech therapist or otolaryngologist, that those responsible will know the option of libras and its advantages. However, many caregivers have not had the opportunity to be referred and have discovered these institutions on their own.

In a fragment from the book *Seeing Voices - a journey into the world of the deaf*, Oliver Sacks reports that “I was disappointed to find that many deaf people never acquire the skills of good language or thinking and that a wretched life may be waiting for them.”^{13:10}

Sacks makes this point because deaf children from hearing families are at risk of

language deprivation since they cannot grasp what is happening around them due to lack of communication with their parents. Added to this is the difficulty of establishing strong enough emotional bonds between parents and children in this adversity. However, this will only happen if the family is not properly oriented, and the child is not referred for adequate care¹⁷.

It is common, still that some forms of communication between the deaf and his hearing family is established, such as lip reading, gestures, or even the use of so-called homemade signs, to maintain communication in the family nucleus¹⁸.

It is important to note that Libras is a sign language. Therefore, it is incorrect to compare the signs of Libras with simple gestures or mimics since it has specific grammar and even each country has its own language for deaf people. In Brazil, Libras was recognized as the official language of deaf people through Law No. 10.436/2002¹⁹.

When parents discover that their child is deaf, they need to learn how to deal with this sometimes-unexpected change. Sharing their concerns with others who are also going through the same stage - shock, reaction, and adaptation, can aid in understanding this new moment in family life. Based on the recognition and understanding of feelings, as can be seen through the interviews carried out at IRES, the caregivers exchange experiences, come to accept the established situation, and replace the feeling of sadness with love.

Health professionals are responsible, during the process of working with the deaf person and his family, to provide sufficient and reliable information and guidance, clarifying all aspects related to deafness. It is, therefore, a challenge for the health professional, being necessary, still, that he knows the cultural and linguistic peculiarities of the community in which his patient is inserted, so that, in this way, interpersonal relationships favor the process of care²⁰.

With the interviews it was possible to infer that a large portion of health professionals is not prepared for the early diagnosis of deafness, and that there is still a considerable gap to achieve completeness in the care of these people, especially with regard to the reception of the family member, with all his doubts, questions and insecurities, because the care of the deaf person and his family requires that it be considered the sociocultural and emotional state of these.

It was also evident in the interviews that early intervention is a *sine qua non* condition for the child's development, thus avoiding deficits in the social, linguistic, and other areas, and allowing the family to be able to make more assertive and/or conscious choices.

This study reflects the experiences of a group of family members, and thus may not portray the reality of other groups that deal with the deafness of their loved ones in other parts of the country; contributes to the literature on the subject that is still scarce, allowing discussion of the privileged role that the health professional must positively influence the lives of deaf individuals and their families.

FINAL CONSIDERATIONS

Health professionals greatly influence the choice of parents / guardians to use Libras, although they still do so with great difficulty, because they are unaware of the potential of the language. It is believed that the biologist view of deafness makes them favor the guidance for the use of other strategies, namely: cochlear implant and hearing aid.

It is also believed that the lack of knowledge of the potential of Libras for the development of the individual by health professionals results in poor information about its use within the family, delaying learning and making interpersonal relationships even more

difficult, because in cases of profound deafness the possibilities with the use of hearing aids and cochlear implant are null.

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