



Care challenges for deaf people experienced by hearing family members: an exploratory study

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ABSTRACT

Objective: to identify the difficulties experienced by hearing family members in relation to caring for the health of deaf people. **Method:** exploratory, qualitative study, conducted in June 2018, with six family members of deaf people. Data were collected in the participants' homes, by means of semi-structured interviews which were later submitted to content analysis. **Results:** the relationship between the deaf person and the family is influenced by the communication strategies used. The main reported difficulty was the effective establishment of communication between health professionals and the deaf person. Although, the family is an indispensable "resource" which helps to overcome this difficulty, they are not always able to express the exact symptoms experienced by the family member. **Conclusion**: Hearing family members accompany their deaf family members in most visits to health services, due to the absence of professionals who communicate in Libras, and health care is compromised for family members who do not communicate in Libras which causes insecurity.

Descriptors: Family Relations; Deafness; Family; Nursing.

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INTRODUCTION

Communication is fundamental in the life of the human being, as it enables interpersonal relationships and daily social interactions. Hearing loss (HL) can interfere with communication and the acquisition of the language used by listeners⁽¹⁾. Deaf people, in most cases, have severe HL, resulting in little or no hearing, and use sign language as their means of communication⁽²⁾.

Deaf people can understand the world through eye contact. For them, the use of sign language and writing, allows their cultural, cognitive and social development⁽³⁾.

In this regard, family also plays a relevant role, especially during the individual's educational process and influences the deaf person's personal development. Family is the first human support network, governed by values, beliefs, goals and behaviors. Through communication, their family helps them to develop their own personality and establish social relationships with the community⁽⁴⁾.

However, when communication is impaired due to HL, hearing parents are faced with an unknown situation, as in most cases they have never or had little contact with deaf people and in general, communication interactions are few, impoverished and often with failures, because they are not fluent in sign language⁽⁵⁾. Thus, more than 90% of deaf children are from families of non-deaf parents⁽⁴⁾. This collision of language culture triggers changes in the quality of communication of family members, discrepancy of information in relation to health guidelines and negative emotions and harmful responses to mental health ⁽⁶⁾. The Brazilian Sign Language (Libras) is the main means of communication used in deaf culture, and supports the relationship between deaf people and society, enabling their inclusion in the community ⁽⁷⁾.

It should be noted that parents who do not accept their child's HL, or even who do not learn Libras, tend to use only mime to communicate with them. However, this conduct hinders adequate communication with the external environment, because by using the same language, the deaf person's friends and the deaf community are a reference full of emotions, thus establishing a model of the deaf person's individual identity⁽⁸⁾.

With regard to health services, it is noteworthy that there are few professionals or interpreters who communicate in the deaf person's own language⁽⁷⁾, which requires that a hearing companion be present during the consultations. In these cases, communication is made with this companion and not with the deaf user⁽⁷⁾, which can limit access to the appropriate service as well as guidelines for performing self-care. Sometimes, the family member plays this role of mediator between the deaf person and the health professional, which makes it even more important to establish clear communication, so that health care is not negatively affected. Given this context, the following questions arise: How do family members experience the process of care in relation to the health needs of the deaf person? What difficulties do they experience in the communication process? In order to answer these questions, the present study proposes to identify the difficulties and challenges experienced by hearing family members in relation to the health care of deaf people.

METHOD

Exploratory research, with a qualitative approach, carried out in a municipality in the northern region of the state of Paraná, Brazil. The study participants were six family members, identified as the "main caregiver" of young people with profound deafness, included in the study, according to the "snowball" method⁽⁹⁾. The first participating family member was appointed by a Libras interpreter who works as a teacher at a school for the deaf. Initially, she informed the family member about the research, and investigated the interest in participating in it. Upon agreeing to participate the family member gave the researcher her contact number so that she could schedule the day, time and place for the interview. This first participant indicated other family members who met the inclusion criteria previously established: being a hearing family member and primary caregiver of a deaf person.

Data were collected in June 2018, by means of semi-structured audio-recorded interviews, after authorization. The interviews were carried out at home, after prior appointment by telephone, and lasted an average of two hours.

A script was used during the interview with objective questions addressing sociodemographic data and open questions related to communication between hearing family members and the deaf individual. In addition, three support questions were used to achieve the proposed objective: Do you have any difficulties in communicating with your deaf relative? Comment. Talk about the difficulties related to health care for your deaf relative? What is the interaction of other family members with (name of the deaf) like? The interviews were transcribed in full, and subsequently subjected to thematic content analysis, respecting the stages of pre-analysis, material exploration and treatment of results and interpretation⁽¹⁰⁾.

The analysis started with a floating reading of the interviews in search of hypotheses and systematization of ideas. Next, the material was explored through the categorization and identification of the registration units for the purpose of codification. Finally, the results were treated and interpreted, culminating in the elaboration of the categories ^{(10).}

The research followed the ethical principles of Resolution 466/2012 of the Ministry of Health and its project was approved by the permanent research ethics committee with human beings (Opinion nº 2.623.505). Participants were informed about the research, and agreed to participate by signing two copies of the Free and Informed Consent Form. In order to guarantee privacy and confidentiality, the participants were identified with the letter F (family member), an Arabic number, according to the sequence of the interviews, followed by the existing family bond.

RESULTS

The deaf participants were aged between 22 and 54 years old, studied at a deaf school and learned to communicate in Libras since childhood. Only one of these had been using a hearing aid for a year. The family members participating in the study are all female, with an average age of 41 years and a family income of three to five minimum wages (Chart 1). Two categories emerged from the analysis of the participant statements, which will be described below.

Communication strategies and the relationship between the deaf person and their families

It was observed that the family relationship is influenced by the way the communication process is established between the deaf person and the members of their family:

> We managed to have a great relationship by the ease of communicating. (F4, daughter)

> Great, I'm always nearby [...], so I don't see any difficulty, I don't think it's something that may hinder our relationship, do you understand? On the contrary, our relationship is very good [...]. (F3, daughter)

> I think the relationship with him is great [...], because we understand each other, I think the question of understanding, even because of the difficulty, [...] because I understand, despite the difficulties I understand, so it makes it easier. (F5, mother)

[...] the relationship is not good because of this communication issue, if I knew Libras, it would be much easier, to say something to him [...].
(F2, niece)

Family members highlighted the importance of knowing Libras and also using different strategies to facilitate communication with the deaf person-

> [...] at the beginning I didn't know Libras [...] when we started it was difficult, what you wanted I didn't know what you were wanting then you cried, lay on the floor, [...] then we learned Libras and it was easy [...]. (F6, mother)

> [...] when she was very small, we had this difficulty, from the moment she started to learn sign language and so did I, so she makes the sign I already understand and everything is OK, so it makes it very easy [...] Libras was fundamental. (F5, mother)

> We know how to write, but we don't know how to sign [...] we have our own familiar gestures, so we created the sign of his name (showing the sign) [...] we invented many gestures, because we don't know Libras. (F2, niece)

Table 1. Characteristics of the family members participating in the study, from a municipality in the northern region of the state of Paraná, 2018.

ID	Relationship	Live together	Age	SC*	Education **	Researched Knows Libras
F1	Mother	Yes	77	SC	ES	Only the alphabet
F2	Niece	Yes	24	SC	ES	Only the alphabet
F3	Daughter	No	27	CC	EMI	Yes
F4	Daughter	Yes	27	CC	EMI	Yes
F5	Mother	No	48	CC	ES	Yes
F6	Mother	Yes	47	CC	IN	Yes

Legend: * SC- Marital Status; SC- Without a partner; ES- With partner ** EMI- Incomplete high school; EM- High school; ES- Higher education. [...] me and my sister we understand perfectly what she says. She can talk outside and yell at us, say something that we understand what she is saying. (F4, daughter)

[...] she goes there and writes on her cell phone and sends it to me [...] then she writes there and shows it. (F6, mother)

[...] sometimes a medicine arrives, I take it and write on paper and stick it on the medicine for him to pay attention [...] he hears many things I do. (F2, niece)

[...] there are some apps, we write and the character signs in Libras, we always find a way, we have to understand. (F2, niece)

[...] like a child how to communicate with your uncle? you have to go there and tell your uncle [...] (F2, niece).

However, sometimes, the family feels distressed and sad for not being able to communicate properly:

> [...] it is a person who is present, [...] everyone likes him, but at the same time he is not present, no matter how much he is here with everyone. Sometimes we talk about something in the kitchen he didn't hear, and sometimes nobody goes to tell him, you know, but he didn't hear. We know that he did not hear [...]. (F2, niece)

> [...] sometimes I feel sad because I can't get through to him, I cry a lot [...] there are some situations [...]

that it is difficult to talk to him [...]. (F2, niece)

There was a difference in the experiences of difficulties influenced by the early search for the Libras course, and in relation to family members who had not done the Libras course. It is noteworthy that in the case of children of deaf mothers (Codas), the learning process in Libras occurs spontaneously and without difficulties; in these cases it happens with the younger siblings of the deaf person, grandchildren, i.e., family members who have more contact, a fact also observed with family members who use gestures as a communication strategy.

> [...] from the moment I had her, I had the problem, so I started to learn Libras. (F5, mother)

> [...] I can't remember, because since I was a little girl my mother has been talking since I was 1 year old, we started doing it, it's like learning to speak, so we learned to speak with signs, so it was something natural. (F3, daughter)

> [...] so much that our children know how to make signs it is also more because when they were very young my mother also used to teach. (F4, daughter)

> [...] she has a second language, because since she was a little girl, she always knows everything, I say she knows more than I do, and now I have my granddaughter too, and I think she will learn everything too,

because it is usually passed on [...]. (F5, mother)

[...] I grew up watching, it's not like my mother who had to learn later [...] so I think I can speak better than my mother (F2, niece).

The learning process in Libras is constantly improving, and the deaf family member is the main educator. In this way, the bond and rapprochement between the members is established from living with the language.

> [...] I think it was a process, so much together that there was no snap thing: I learned and that's it. Especially because [...] today, a lot has already changed, it's like medicine, stop and you forget, so you have to have that contact. (F5, mother)

> [...] she taught me, she grew up and there is a different sign that I didn't know and she told me, new ones, there are always new ones and she taught me, she teaches me until today, teaches me Libras [...] it is always changing [...] (F6, mother)

On the other hand, it was observed that when the deaf person does not grow up with the hearing family member there is greater difficulty in communication and in the relationship.

> [...] he (stepfather) has a little more difficulty, because when he came, she was already big, so he didn't have this whole process. (F5, mother)

> His brother knows little, he writes, he uses the alphabet more, a little sign [...]. (F6, mother)

[...] he (father) communicates little [...], he doesn't know much [...]. It is more that I include her in the middle of the conversation [...], sometimes they say something there, but it is more me, that part is difficult [...]. (F6, mother)

These difficulties are also experienced in contact with more distant family members, and that is why those who have greater contact and ease of communication with the deaf become an intermediary in the dialogue,

[...] my sisters don't know how to talk to her, [...] they speak to me and I speak to her, you know. (F6, mother)

[...] my uncles know the basics [...], but when they don't know the question, they say that my mother reads too, and then she tells me what the sign is, they do it right, everything is fine, but she communicates normally. (F3, daughter)

However, in some moments the deaf relative ends up isolated:

[...] parties are usually like this, my mother [...] says that there comes a time when we hearing people start talking only between us and leave her aside. Then she says that she has to have another deaf person to also be able to talk, because [...] there comes a time when we get there, [...] but without realizing it, you know [...] (F3, daughter).

[...] we went to some family gathering, everyone talking, I had already talked to him and then out of nowhere I saw him sitting there on his cell phone talking to his friends [...] he should have been there among us chatting with us [...] because he is deaf and cannot join in quickly, because times like these, I need to stop to talk to him [...] I can't talk to you like that and talking to him to make him understand. (F2, niece)

It is important to mention that when family members are unable to communicate properly, they use other instruments such as: speech, writing, cell phone applications that translate into Libras, and contact, in this case mostly used by children.

> [...] me and my sister we understand perfectly what she says. She can talk outside and yell at us, she says something and we understand what she is saying. (F4, daughter)

> [...] she goes there and writes on her cell phone and sends it to me [...] then she writes there and shows it. (F6, mother)

> [...] sometimes a medicine or something arrives, which I take it and write it on paper and stick it on the medicine for him to pay attention [...] many things I do he hears. (F2, niece)

> [...] there are some apps, we write and the character does the signs in Libras, we always find a way, we have to understand. (F2, niece)

> [...] like a child how to communicate with your uncle? you have to go there and tell your uncle [...] (F2, niece).

The family as a "resource" for the health care of the deaf individual

The study participants stated that during care at health services, it is often necessary to accompany the deaf family member, especially at the first consultation, as most health professionals do not know how to communicate with the deaf individual.

> [...] she says that the nurse or the doctor cannot communicate with her and does not understand what she wants to say, sometimes she has difficulty, sometimes she even gives up, goes away and asks us to go one day with her. (F3, daughter)

> [...] I accompany her, too much sometimes, she needed to be more free. (F6, mother)

[...] a family member always goes with him at the first and the last time he goes to a health service, to start a health treatment. He went to the dentist to do the treatment, a family member with him[...], let's do this treatment then on the days of the treatment he went alone, he left the name, contact, phone, of somebody if they needed to call [...]. (F2, niece)

Just ask me, they don't know anything, nothing, nothing, this is difficult, this is difficult. (F6, mother)

It was possible to verify in the statements that, due to the fact of knowing how to communicate in Libras, the family member feels secure in passing on health information, to the professional who requests it and to the family member without difficulties. [...] the way she passes the information on to me is the way I communicate it to the doctor, [...] when the doctor says something to me, I pass it the way he communicates it to her. (F3, daughter)

[...] because since I found out, I've already taken a course, so I understand [...] she can transmit and I can understand. (F5, mother)

However, family members who have difficulty communicating feel insecure about passing on information during visits to health services.

> [...] he says he has pain, pain in the head (shows the gesture), but then, it is not a simple headache, we know, [...] or you have pain in your stomach [...] but he doesn't know if it's the bladder, [...] so we know that here is the stomach, which is a gas pain, [...] and he can't say, if it's a gas pain burning or if it is a pain that is throbbing [...] I need the exam to be sure what he has. (F2, niece)

However, they emphasize that because health professionals are unable to communicate directly with the deaf individual, it makes important actions such as prevention guidelines difficult, since the family member cannot perform them alone:

> [...] due to the lack of communication even [...] health prevention is an issue that I think could improve us by being able to pass it on to him, which is prevention [...] making him understand that you have to go to the doctor to prevent it is a good thing (F2, niece)

DISCUSSION

Adequate communication is essential for quality family interaction to occur, the presence of HL during childhood can impact on emotional, social, bonds, and language development⁽¹¹⁾. Thus, considering the deaf individual and their families, the use of sign language favors family interaction, the exchange of information and facilitates coexistence. When family members do not use it, the bonds are permeated by difficulties and weaknesses, perpetuating in all life cycles ⁽¹²⁾.

In view of the child's hearing loss diagnosis, the two youngest mothers participating in the study sought to learn Libras immediately. In contrast, some hearing parents took a long time to look for a Libras course, which causes communication to be more superficial⁽⁵⁾. Family members highlighted the use of other resources, as mentioned in the statements of F2, F4 and F6 that favor interaction with the deaf individual, which demonstrates the concern with establishing effective communication so that the bond is not harmed by the HL of their family member.

Despite the communication barrier between hearing and deaf family members, four of the six family members in this study reported that they know how to communicate using Libras, and are concerned with including the deaf family member in family events and encourage their interaction. However, a study carried out in São Paulo showed that no family member had dominion over Libras, resulting in the communication between family members and the deaf person was superficial and meaningless⁽¹²⁾. The use of Libras for deaf people is an essential tool for orientations, education, exchange of experiences and health care to take place properly.

Regarding the health care process, it should be noted that Decree No. 5,626, of December 22, 2005, which regulates Law No. 10,436 / 2002, and establishes that health services must have trained professionals to provide assistance to deaf individuals must be pointed out. According to this decree, at least 5% of health professionals in public establishments must be qualified to employ and interpret Libras⁽¹³⁾. It is noteworthy that accessibility to language should be offered by health services to all people with HL, whether they are Libras users or Portuguese speakers, due to the heterogeneity of the deaf population, which needs access to health services, that includes all communication modalities.

Despite the existence of decrees and laws in the Brazilian legal system, which establish Libras as a communication tool and ensure the provision of health services to deaf individuals that meet their needs in public institutions, it appears that they have not yet been sufficient to dissipate communication barriers⁽⁷⁾. The difficulty the deaf family member has with communicating with health professionals is demonstrated in the statement of F3. This likely occurs due to the lack of specific legislation that requires the presence of interpreters in health care consultations and the mandatory discipline of Libras during the training of all health professionals.

It should be noted that poor communication between the professional and the deaf patient is associated with lower quality of care, reduced patient satisfaction, increased incident rates, as well as subjecting the deaf individual to health risk conditions⁽¹⁴⁾.

Research carried out in the United Kingdom, found that the deaf population has worse health conditions when compared to the general population, with probable underdiagnosis and undertreatment of chronic conditions, triggered by the communication barrier ⁽¹⁵⁾. In view of the difficulties that health professionals have in relation to communicating with the deaf, they most often go to health establishments accompanied by heaing family members, who act as the communication intermediaries⁽⁶⁾, as observed in the statements of F6 and F2. This fact sometimes limits independence and autonomy in relation to their own health and care actions for the deaf individual ⁽⁶⁾.

In the report of F2, it is observed that care to the deaf patient is limited to the health complaint due to the difficulty of communication, pointing out the need to address aspects related to health promotion and disease prevention. A study carried out with American deaf people pointed out their limited access to health services, especially due to communication barriers and low education, a fact that increases the use of emergency services, with complications in the state of health⁽¹⁶⁾.

Thus, the importance of complying with current legislation is reiterated, i.e., at least 5% of health professionals are prepared for communication in Libras in an adequate way for deaf people to access health care. In this context, a study carried out in Mississippi highlighted some strategies that can benefit communication in the health service, such as: the development of services, systems and policies that encourage awareness about communication barriers, in order to provide improved communication, ensure adequate access for professionals to auxiliary communication tools, hire interpreters in health units, increase the communicative competence of health professionals and learn during sign language during academic training language ⁽¹⁷⁾.

CONCLUSION

The family relationship of the hearing members with one of the deaf members, presented itself in a specific way, with communication in Libras being the main form of approximation and bonding. Family members who do not use Libras resort to their own family gestures, in order avoid harming the family relationship and interaction due to the family member's HL.

The same occurs in relation to health care, a hearing family member most often accompanies the deaf family member in their journey through health services, due to the lack of interpreters and trained professionals trained to communicate in Libras in health establishments, by doing so, the family member acts as intermediaries of the dialogue. When the family member knows Libras he has no difficulty. On the contrary, when the family member is insecure in relation to passing on health information and prevention and promotion guidelines, this causes the deaf individual to receive restricted knowledge regaeding the health-disease process.

The results of the present study support reflections regarding the need for strategies to be adopted by health establishments, which enable comprehensive care for the deaf individual and facilitate the professionals' access to their real needs, in order to develop actions that enable the promotion of autonomy and self-care

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