# PERCEPTION OF PERSONS WITH SEVERE OR PROFOUND DEAFNESS ABOUT THE COMMUNICATION PROCESS DURING HEALTH CARE

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*This study describes a qualitative approach with the objective of characterizing the perceptions of people with severe or profound deafness about the communication process in the context of health care services. Study participants were 11 people with severe and/or profound deafness, who were interviewed using Brazilian sign language (LIBRAS). The interactions were videotaped and then transcribed. Care was taken to maintain the grammatical construction which was characteristic in the expression of each person. Three categories emerged from thematic analysis: Understanding, Need for Mediation, Feelings. Deaf persons do not achieve effective communication in health care, during which they experience negative feelings. Hence, the presence of a professional interpreter is needed.*

*DESCRIPTORS: communication; sign language; nursing*

# PERCEPCIÓN DE LA PERSONA CON SORDERA SEVERA Y/O PROFUNDA ACERCA DEL PROCESO DE COMUNICACIÓN DURANTE SU ATENCIÓN DE SALUD

*La finalidad de este estudio descriptivo con aproximación cualitativa fue caracterizar las percepciones de personas con sordera severa o profunda sobre el proceso de la comunicación en el contexto de su atención por profesionales de salud. Participaron once personas con sordera severa y/o profunda, que fueron entrevistadas mediante el lenguaje brasileño de signos (LIBRAS). Las interacciones fueron grabadas en cintas VHS y transcritas, manteniéndose la construcción gramatical característica de su expresión. Mediante análisis temático emergieron tres categorías: Entendimiento, Necesidad de Intermediación y sentimientos. El sordo no alcanza una comunicación eficaz durante la atención de salud, en la cual experimenta sentimientos negativos, necesitando la presencia de un profesional intérprete.*

*DESCRIPTORES: comunicación; lenguaje de signos; enfermería*

# PERCEPÇÃO DA PESSOA COM SURDEZ SEVERA E/OU PROFUNDA ACERCA DO PROCESSO DE COMUNICAÇÃO DURANTE SEU ATENDIMENTO DE SAÚDE

*Este estudo descritivo de abordagem qualitativa teve o objetivo de caracterizar as percepções da pessoa com surdez severa ou profunda sobre o processo de comunicação no contexto do seu atendimento por profissionais de saúde. Participaram 11 pessoas com surdez severa e/ou profunda, as quais foram entrevistadas usando-se LIBRAS. As interações foram gravadas em fitas VHS e transcritas, mantendo-se a construção gramatical característica da expressão destas pessoas. Mediante análise temática emergiram três categorias: Entendimento, Necessidade de Intermediação e Sentimentos. O surdo não tem alcançado uma comunicação efetiva durante o atendimento de saúde, no qual experimenta sentimentos negativos, necessitando da presença de um profissional intérprete.*

*DESCRITORES: comunicação; linguagem de sinais; enfermagem*

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## INTRODUCTION

Communication is an interaction process in which we share messages, ideas, feelings and emotions. It occurs by means of written and spoken language, besides non-verbal mechanisms like gestures, corporal expressions, images, touch and other signs. Communication can also be considered an essential instrumental for the development of humanity and an important tool for interventions in the health area[1-2].

In nursing care, conscious communication is needed, making efforts to decode, decipher and perceive the meaning of the message patients are sending; that is the only way to identify their needs. Moreover, effective communication allows nursing professionals to help patients to conceptualize their problems, cope with them, visualize the experience and even help them to find new behavioral patterns[2]. In this perspective, communication can become a form of help.

In some situations, nurse-patient communication can be impaired by factors inherent in the patient, such as the impossibility to talk, understand or listen. These are challenging situations, which have been the object of research, in which the basic problem is nursing professionals' difficulty to establish effective communication with these patients. In this context, professionals use any alternative forms they can identify besides verbalization, such as touching and reading facial and corporal expressions[3-4].

People with hearing impairments can face problems related to effective communication in health care. There are approximately 5.7 million hearing impaired (HI) persons in Brazil. About one million of them present severe deafness[5]. Although many studies have focused on non-verbal communication[1,4,6], there exists little literature about communication between health professionals and deaf populations. Like any other population, the hearing impaired need health care, which is not necessarily connected with deafness itself. Nursing faces communication difficulties when delivering care to hearing impaired patients[7]. In general, in order to interact, professionals use signs and gestures which they believe to be adequate to transmit what they are trying to express to the deaf person, or they ask help from a companion to mediate in communication. However, it should be clarified that the characterizations of non-verbal behaviors applied to hearing populations are not completely applicable to deaf groups[8].

Hearing impairment (whether congenital or acquired) consists in a decreased capacity to perceive normal sound. Individuals whose hearing is not functional in common life are considered deaf. The different levels of hearing loss can be classified as: light (loss of up to 40 dB); moderate (loss of between 40 and 70 dB); severe (loss of between 70 and 90 dB) and profound (hearing loss of more than 90 dB) deafness[9].

Health professionals tend to use rudimentary forms of communication with this clientele, unless a companion is present and helps them by mediating communication. In very rare cases, both the health professional and the severe or profoundly deaf patient master LIBRAS (Brazilian Sign Language).

Sign languages differ from oral languages because they use a visual-spatial instead of an oral-auditory means or channel. Signs are constituted by the combination of forms and hand movements and reference points in the body or space[10]. Brazilian Sign Language (LIBRAS) is conceptualized as the form of communication and expression, in which the visual-motor linguistic systems, with their own grammatical structure, constitute a linguistic system for the transmission of ideas and facts, originated in communities of Brazilian deaf persons[11].

Even when using LIBRAS, difficulties may appear in communication with severe or profoundly deaf persons, especially when the nursing team needs to develop health education actions in this population by means of sign language, as the sentence constructions hearing people tend to use do not always correspond to the lexical universe of people who are deaf since childhood[12].

The question brought up in this research emerges from deaf people's difficulties to express and receive more complex messages and from the fact that, until now, research has focused on health professionals' perceptions in situations of communication with this clientele[7,13]: how do people with severe or profound deafness perceive the communication process established in their health care?

We believe that this study can provide contributions to support the planning of local (in institutions) and wide-ranging (public policies) strategies, with a view to improving the quality of

health care for this clientele through more effective communication. Moreover, we hope to produce information that can orient health teaching for professional training, as well as guide future research strategies involving this population group.

## OBJECTIVE

This study aimed to characterize the perceptions of people with severe or profound deafness about the communication process with professionals in the context of their health care.

## METHODOLOGY

We carried out a descriptive study with a qualitative approach. Participants were 11 deaf persons over 18, who attended a religious institution in Goiânia (GO), Brazil, were literate or semiliterate and communicated by LIBRAS. This research project was approved by the coordinator of the place of study and by the Research Ethics Committee at the Federal University of Goiás (UFG).

During all study phases, contact with participants was always mediated by an interpreter fluent in LIBRAS.

Initially, we presented the research proposal during one meeting of the deaf group and invited all members to participate. During subsequent meetings, we inquired about their interest in participating and scheduled a date and time for an interview, according to the subjects' availability. In this context, we again explained the research and gave the subjects the Free and Informed Consent Term, who manifested their agreement in writing.

Data were collected by means of a semistructured interview. The script addressed the following topics: I - Sociodemographic data (age, gender, education, profession/occupation, family income); II - Report on health care delivery during which the individual perceived facility to understand and be understood; III - Report on health care delivery during which the individual perceived difficulty to understand and be understood and IV - Description of the communication process the individual used with the health care professionals.

Data for the first topic were filled out in writing by the interpreter, while the descriptions of health care delivery were video recorded. The interviewees' syntactic constructions were respected in the transcription of the interviews. The tapes will be safely stored by the responsible researcher for five years, in compliance with Resolution 196/96 by the Brazilian National Health Council[14] and then destroyed.

Participants' discourse was submitted to thematic analysis[15]. For the sake of preserving their anonymity, letter and cipher codes were used. The letter S corresponds to the subject and the number to each participant's designation.

## RESULTS AND DISCUSSION

Study participants were seven men and four women, between 20 and 60 years old. The predominant age range was between 31 and 50 years old. All subjects had severe or profound deafness, occurred before the first year of life (eight participants). Most participants earned more than two minimum wages per month and had finished at least basic education. As to their profession, three participants were seamstresses, two were LIBRAS teachers, one Reverend (retired), one Missionary, one graphic designer, one student, one deboner and one without profession.

During their testimonies, participants explained why they had sought health care on the occasion of the experiences they reported. The most frequent repeated reasons referred to dental treatment, headache, stomach ache, pregnancy-related motives, learning to talk, earache and cough. Asthma, diarrhea, fever, throat infection, heart problems, gynecological treatment, kidney problems and vomiting were each mentioned once.

After transcribing the interviews, 302 recording units were identified (speech fragments with a complete meaning of a course of action). Three categories emerged from thematic analysis: Understanding, Need for mediation and Feelings, presented and discussed below.

### Understanding

For communication to occur, there is a need to comprehend and be comprehended which, in the lexical universe of the hearing impaired (HI) means *understanding*. When deaf people seek health care, they are faced with situations that interfere negatively in the quality of the communication process.

The deaf experience difficulties to understand professionals' language because these generally do not take care to show their mouth, speak fast or use technical terms which deaf people do not understand.

*Deaf has serious problems, doctor does not understand because deaf talks face to face (S9).*

*I say: please, take off mask I don't understand (S11).*

*Doctor talked and I said: calm, talk fast, talk slow (S2).*

*Difficult, doctor difficult, doctor talks difficult... (Technical terms) (S4).*

The interviewer has to avoid hiding his/her face and lips with his/her hands, hair and objects. The same is true for pens, prescriptions and surgical masks. Professionals should also look directly at the patient while talking[16]. Some deaf people can read lips, which greatly helps the professional-patient communication process. However, when professionals do not pay attention to the fact that hiding their mouth impedes lip reading, yet another communication barrier appears.

Deaf people often do not manage to read what professionals write because there are difficult words, technical terms; because the deaf does not know Portuguese well or because the professional's handwriting is illegible.

*Writes angular letter, look I don't understand (S6).*

*Word writes name drug to take, difficult (S5).*

Using writing can be useful during medical interviews for communicating with these patients. However, for complex explanations, it is common for the deaf population to be less instructed than the population in general[17]. Therefore, professionals need to dedicate more attention and care to explain technical terms to the deaf. It should be reminded that legible handwriting avoids misunderstandings as well as medication errors:

*Time of medication I mixed up (S2).*

Difficulties to establish understanding relate to the fact that professionals do not understand the deaf either. *Professional does not understand me because difficult, Libras difficult (S4). He looks at me sees signs does not understand (S9).*

Although Law No 10.436, issued on April 24th 2002, which regulates the use of LIBRAS, determines that public institutions and public health service concessionaires have to guarantee adequate care and treatment to people with hearing impairments[11], health professionals do not know the language and there are no interpreters available at the health services.

Sometimes, health professionals do not understand what the deaf write because the grammatical construction they use is different, or because the hearing impaired (HI) do not master written language.

*I write, if woman looks thinks difficult... did not understand (S3).*

Although Brazilian Sign Language and other related resources for expression are recognized as a legal means of communication and expression[11], health professionals are not obliged to know or understand LIBRAS. On the other hand, deaf people who communicate in sign language use grammar and vocabulary that is different from Portuguese. Hence, people who were born deaf in Brazil may be fluent in LIBRAS and not in Portuguese.

The HI describe the lack of mutual comprehension as "blocked communication" or "communication does not combine".

*Stomach hurts, go to doctor, talk, communication does not combine nothing (S5).*

In some situations, the deaf understand the health professionals: when they use LIBRAS, write easily, talk slowly and when the deaf can read lips.

*Now I have friend doctor knows signs, takes care of everything (S7).*

*I have already been to deaf dentist, woman graduated dentist, good (S9).*

*Communication easier because learns, phonoaudiologist speak slowly (S2).*

*When deaf reads lip easier (S5).*

Most interviewees mentioned that the communication problem would end if the health professional could use LIBRAS. This finding is similar to another study[17], in which the deaf also put forward the need for health professionals who know how to use LIBRAS.

Another situation in which the deaf indicated easy understanding during communication was when not many explanations were needed on both sides. This was particularly the case in dental care.

*He wrote: water, spit I understood (Referring to the dentist) (S7).*

Professionals understand the deaf when they see signs of disease, when the deaf makes characteristic gestures ("universal" within a given sociocultural context) and when the deaf writes.

*When fever, coughing easily, doctor sees and knows (S5).*

*I went tooth problem, saw, treated, wrote, tooth very good (S3).*

*I pointed at belly, face of pain (S2).*

When deaf people seek health care and show clinical signs of disease, it is easier for health professionals to detect what is going on; however, in cases of disease without any apparent cause, in which a more thorough patient history is needed, the situation becomes more complicated. Deaf people can use gestures and expressions that are not part of LIBRAS, but which are universally understood, such as pain expressions, pointing at the site and defining the type of pain. Patients who have been alphabetized in Portuguese can also write although, as mentioned above, their grammatical construction is different. Thus, professionals should patiently try to understand what the deaf want to say and, if they do not understand, they should not be afraid to admit that they have not understood and ask again.

Health professionals need general and specific communication skills for care delivery to hearing as well as non-hearing patients. In many aspects, phenomena that make communication between the HI and health professionals more difficult are the same as for the hearing population, mainly when the persons involved are not talking face to face, with access to the face to face visual field (especially the mouth), using terminology that patients do not understand.

Need for mediation

Most of the times, the deaf need people who translate their emissions to professionals and vice-versa, leading to the need for mediation. The mediator is configured in family, friend and professional interpreters.

*Family helps, goes together talks doctor (S6).*

*Our family combines, because knows signs (S7).*

Some characters appear in this context, such as the mother, father, sibling, child, husband. However, the mother undeniably stands out and appears in 30 of the 55 recording units about family.

*Only mother always together, I already got used (S9).*

Sometimes, the companion is also deaf but has better mastery to communicate with hearing people. One participant mentions that her deaf husband accompanies her and serves as a mediator (the husband has a higher education degree, masters reading and writing and can read lips). *I together deaf husband, the two together he explains me I understand (S7).*

Sometimes, relatives instinctively "talk on behalf of the deaf" or on their request, as shown by one of the interviewees' discourse: *father together asked doctor, communicate with me no, ask father talk me (S8).*

Although family members represent help in most cases, they can also represent a problem when they do not allow the deaf to participate as an active agent in their treatment, when it is the deaf's companion who explains his/her health problem to the professional and also receives orientations; thus, the deaf may not even have the opportunity to expose their doubts[17].

Another family-related issue is that deaf persons become dependent, as the family cannot always accompany them when they need health care.

*But without mother bad life, problem sick, occupied, travels, I alone lost (S9).*

*Family is bad, father occupied because works all the time (S5).*

Participants' reports also reveal friends as mediators in this communication process. They can be neighbors or even another deaf person with more instruction or experience.

*Deaf helps other deaf (S3).*

*I know friend who reads prescription, sees time (S4).*

Although not accessible to most HI, the interpreter is the preferred option among all mediators.

*Interpreter better signs than mother, but perfect no (S10).*

*Important thing, dentist, nurse, health, each work city need interpreter in all place, future better (S5).*

The presence of an interpreter is also important to health professionals, mainly for collecting the patient's history[16].

The interpreter can help the deaf, even without accompanying them during health care, as two interviewees mentioned:

*I sometimes asked interpreter to write everything, took to the dentist, handed in to person read understood (S9).*

*I seek interpreter, if interpreter cannot calls the Professional, they talk he understands... (S3).*

The deaf's reports suggest that the availability of an interpreter in hospitals would be of great help in the communication process.

*Hospital needs to have interpreter I go alone (S9).*

In the same way, another study[17] also identified the need for the presence of a LIBRAS interpreter during doctor's appointments.

Deaf people complain about difficulties to find interpreters. As mentioned, some of them have

interpreters in their family, while other pay a qualified interpreter when necessary, but they do not always have the money to pay. Sometimes, the family cannot accompany them and, at other times, the interpreter is not available.

*I gave up asked interpreter to go together [...] Because difficult, interpreter does not have (S9).*

According to Decree No 5626, issued on December 22nd 2005, which regulates the LIBRAS Law[18], care delivery to deaf or hearing impaired people in the public health network or in public health care concessionaires must be carried out by professionals who are trained to use LIBRAS or for its translation and interpretation. This legislation represents an important conquest for the deaf population, as indicated by the expectations revealed in participants' testimonies.

Feelings

Health professionals' lack of dialogue and listening towards (hearing) health service users has been indicated as remarkable and an obstacle for quality care. For deaf people, breaking this context, with all of the limitations it entails, can be extremely challenging, creating different feelings. Participants' discourse demonstrates that the communication process generates fear when the deaf go to health care without any companion.

*I alone was afraid because doctor understand nothing (S9).*

The deaf also talk about their fear of being deceived. When they seek health care, like any other individual, they need to fill out files, forms and sign them. Many deaf people have little instruction and do not manage to read and understand these documents. In education institutions for deaf people, they are taught not to sign any type of document which they do cannot understand. Hence, these files are yet another barrier to their care.

*Secretary called to fill out file, no, dangerous because I write little (S7).*

Because they do not understand what professionals say and write, do not understand the prescription and assess that professionals do not understand them, the deaf are afraid that they will take the wrong medication and/or that the disease will continue.

*Can talk doctor he prescription can wrong medication, disease continue I fear (S9).*

Another feeling the deaf mentioned was suffering ("deaf suffers"), because they feel discriminated against in our society where most people can hear, and because they do not have access to an interpreter when they need care. They say *Hearer always better deaf better never [...] For the hearer easy much above, need deaf equal, warn pay interpreter seems discrimination [...] Deaf needs to dream, complain, ask more interpreter. Needs suffering of deaf to end (S10).*

The deaf need professionals to accept their condition, not discriminate against them and remain indifferent. The hearing impaired want to be treated as citizens and as part of society[17].

Both medical and nursing teams and deaf patients themselves indicate communication difficulties for health care[7,16-17]. Thus, there is a need to find means to turn this communication less traumatic on both sides.

The deaf feel discriminated against because they do not receive care that is adequate for their condition, as guaranteed by current laws[11], because they have to queue for a long time before they receive care, since they cannot hear when their name is being called and since professionals, even when they know that the client is deaf, do not pay attention to call him/her in an appropriate way. *I deaf difficult, I second person, I third, fourth... I wait, I wait, because I did not hear (S6).*

Deaf people also suffer because they do not have an interpreter to help them communicate when they seek health care. This situation repeats itself when they are trying to obtain the prescribed medication, when they go to the pharmacist's to buy medicines. They say *there is no interpreter, doctor, things, deaf suffers (S9). Sad hospital, pharmacist's. Pharmacist's sad, ask interpreter woman cannot, difficult (S2).*

All of the difficulties they face generate feelings of anger in the deaf. One participant mentions *I anger because doctor difficult, because talk fast, calls name and takes time because I deaf...(S2).*

The deaf also manifested feelings of happiness and relief when they manage to comprehend and be comprehended. The extent of their joy can be perceived when one of the interviewees says: *I understand, great, I jump with joy, happy (S3).*

During health care, the deaf perceived that professionals also present feelings of anger and get nervous because they do not understand the deaf's communication, who, in turn, request patience with a view to achieving mutual understanding.

*Calm, need patience, I explain again. Doctor very nervous, face different (S2).*

The key to successful communication with deaf persons is to adapt to this situation[16]. Deaf people make suggestions on how to improve their communication with health professionals. The latter should be sensitive enough to be willing to try.

## CONCLUSIONS AND FINAL CONSIDERATIONS

Deaf people have a different culture and language, which must be known and respected in accordance with ethical, moral and legal principles, just like any other citizen. This study presents a perspective on the reality of health care as it is experienced by the deaf. Participants' reports evidence difficulties for adequate health care, due to factors like: absence of adequate mediation; lack of preparation for health professionals who deliver care to deaf people, ranging from their reception until the moment they receive final orientations about care and treatment. Professionals do not pay attention to simple resources, such as showing their mouth while they talk. In the health care context, deaf people feel discriminated against, they are afraid because they do not understand what professionals are saying, evidencing the need for special care.

Participants reveal that efforts to overcome communication difficulties are still based on intuition and interlocutors' good sense. In this unequal relation, particularly the deaf have undertaken the greatest proactive efforts to find measures that can increase mutual comprehension. They demand the presence of an interpreter at health institutions, as recently established in Decree No 5626, issued on December 22nd 2005[18]. In order to put this legislation into practice, there is a need to encourage training courses for health professionals to deliver care to HI, value this training when health professionals are hired in health institutions; offer LIBRAS training at health institutions for active professionals and discuss the communication process with deaf people in undergraduate courses in health. This will stimulate health professionals to become interpreters, making it easier to guarantee the presence of at least five percent of LIBRAS-trained workers, as determined by law[18].

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