

UNDERSTANDING THE DEAF PATIENT'S PERSPECTIVE IN THE DOCTOR-PATIENT RELATIONSHIP

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Abstract: Hearing impairment affects an important part of the Brazilian population, which faces numerous barriers in the accessibility to health services. Problems such as communication failure increase the chances of misdiagnosis, medical record errors, non-adherence to treatment, constraints, suffering and user dissatisfaction. In order for the deaf patient to enjoy quality care, it was necessary, therefore, to have an important focus on this relevant topic. Revisional, this text includes discussions based on scientific research in the health area regarding deaf patients, as well as the difficulties and barriers in the doctor-patient relationship. In view of this, the work carried out aims to point out the main difficulties experienced by deaf patients in the face of the unpreparedness of the health professional, in addition to the constant need for a family member as an “interpreter”, which results in the loss of their independence and privacy during consultations. Through scientific articles taken from renowned platforms in the health area, several proposals and solutions were evidenced, in order to facilitate the understanding and elucidation by the professional regarding the perspective of the deaf patient, so that equity in the quality of care is guaranteed. for all.

Keywords: Deaf, Hearing deficiency, Sign language, Doctor-Patient Relationship.

INTRODUCTION

Historically, people with disabilities were considered either cursed or semi-divine beings, often excluded from the social context and seen only as an object of community charity. In classical antiquity, Aristotle considered language as a vehicle that enabled the very condition of being human, so the person born deaf, for not speaking or understanding others, did not reason. In this context, the deaf were considered worthy of pity and victims of misunderstanding by

society and also by the family itself (DUARTE et al., 2013; NÓBREGA et al., 2012).

A person whose hearing is not functional for the performance of daily activities is considered deaf and is characterized as the reduction or absence of the ability to hear certain sounds and can be classified into two types: conductive hearing loss, which is usually caused by obstructions external ear such as wax plugs, ear canal infections, ruptured or perforated eardrum; and sensorineural hearing loss, which comprises damage to the hair cells of the cochlea. The causes can be congenital, caused by gestational rubella, medications taken by the pregnant woman, heredity and complications during childbirth, such as anoxia (insufficient oxygen supply), or it can be acquired as a result of recurrent otitis in childhood, misuse of antibiotics. and even viruses (MONTEIRO et al., 2017). A person with a hearing loss of up to 40 decibels is classified as having a mild deafness; those with hearing loss between 40 and 70 decibels are characterized as having moderate deafness; on the other hand, severe deafness is defined by hearing loss between 70 and 90 decibels, while profound deafness affects individuals whose hearing loss is greater than 90 decibels (SECRETARIA DE EDUCAÇÃO ESPECIAL, 1997).

The world panorama reveals that 466 million individuals are affected by some kind of hearing loss (WHO, 2011), whereas, according to the 2010 IBGE census (Brazilian Institute of Geography and Statistics), there are 9.7 million deaf people. in Brazil, which is equivalent to 5.1% of the total population of Brazil, who, in almost their entirety, cannot communicate through the official language of the country. Because the verbal code is not normally used by the deaf, they resort to another channel: Sign Language (SL). Despite not having a universal structure, LS is found on all continents and has a

diversified grammatical structure. It consists of a form of communication and expression in which the linguistic systems of a visual-motor nature, with their own grammatical structure, constitute a linguistic system for the transmission of ideas and facts, coming from communities of deaf people. It is as complex as spoken languages, being neurologically structured in the same brain areas as spoken languages. (PIRES et al, 2016)

Such statistics justify the understanding and reception of these individuals in society, in such a way as to adapt the means of treatment and planning, within the scope of health and their respective institutions and collaborators for better training of human resources in the care of these people, optimizing the doctor-patient and their corresponding communication. People who seek health services seek, in addition to welcoming, supportive and trusting relationships with professionals in order to solve their health problem. The deaf individual, when seeking care at the Health Unit, finds his communication with the team as a block. As he does not use verbal language, he communicates through Brazilian Sign Language (LIBRAS), which is little understood by health professionals. In addition, the absence of interpreters on site makes assistance to the deaf unfeasible both in terms of effectiveness and humanization (LEVINO et al., 2013).

METHODOLOGY

The research platforms – SciELO and Google Scholar – were chosen through their authority in academic research processes, in addition to having a wide availability of articles and positive qualifications.

The choice of the SciELO digital library as the database used in the research is due to the regionalization of its articles, focused on journals from all over Latin America and the Caribbean, specialized in health sciences,

among other areas of knowledge. The SciELO database can currently be retrieved by different search tools not restricted to the SciELO portal, such as Google Scholar, PubMed, the Virtual Health Library (VHL), among others. Due to our scope being in the national scenario, SciELO and Google Scholar proved to be the most relevant databases for the study, compared to PubMed.

The other database chosen was Google Scholar. Aimed at academic information, Google Scholar, also known as Google Scholar, facilitates research in a wide and reliable database. He makes use of the bibliography of his platform, searching in theses, articles, dissertations and other productions. Google Scholar allows users to add their own productions. From this database, the platform selects the works that are most cited, thus giving greater relevance at the time of research. Due to the wide range of works published on this platform, its use was very relevant for the collection of references and articles to support this work.

The year of publication, the subject studied and the country of publication were evaluated, so that the review was well developed and coherent with the current situation and with the country of the study. The search terms: “deaf”, “doctor”, “LIBRAS” and “communication” were used to search for the most used vehicles, the quality of information transmission and the data collected in surveys among patients. In addition, the period of publications was restricted to 2010 to 2020, seeking greater engagement in the collection. Those that emphasized the position of the health professional in the face of the situation were discarded, since the intention is the patient’s perspective. Articles whose research was carried out outside Brazil were also excluded, as the national scenario is the field of interest. The preference in the choice was given according to the spatial scope of field

research, and according to the number of participants and variety of data, aiming at a coherent, clear and quality review.

Then, thematic analysis of the articles obtained in research and a selection based on the pertinence of the contents for the area under study were carried out. Data and reports were properly organized and systematized, classified according to their type and elements, in a clear and concise manner.

In the SciELO platform, the terms previously mentioned were used, resulting in 7 related articles, 4 in Portuguese and 3 in Spanish. After an analysis of the titles of the results, 2 articles were selected, as they appear to be related to the proposed theme. After reading, both were selected for the study, since they were talking about the topic. The excluded articles had tangent and non-objective central themes when compared to the focus of the study. It is worth mentioning that all the results presented in the search are published after the year 2013.

Finally, on the Google Scholar platform, with the words “deaf”, “doctor”, “LIBRAS” and “communication”, the result of 10,100 articles was reached. Due to the excessive breadth, the search was limited to research in humans, in the period from 2010 to 2020 and with the addition of the word “patient”, reducing the articles to 2,520. With the still high number of articles available, we chose to choose the most recent works, whose publication took place during or after the year 2018, reaching a total of 572 works. For the desired direction of the study, the abstract of these resulting articles was read and, after careful analysis, 10 articles were selected for the construction of the review.

As for SciELO, the disadvantage was that it retrieved a low number of scientific articles relevant to this topic. The articles retrieved by these banks, however, were relevant in this matter, suggesting greater reliability in

the subject sought, when opting for these bases. The difference in the number of articles retrieved in SciELO compared to Google Scholar seemed to be related to the search method used by each bank, language and the nature of the indexed journals. SciELO has a biomedical focus, with an emphasis on natural sciences and health, mostly in Spanish, showing a much smaller amount of academic articles relevant to our topic. In relation to Google Scholar, the justification is based on the word search methodology and the nature of the journals indexed there, which deal more with human areas than biological ones, and return more national articles.

The 12 articles identified and selected made up the thematic content addressed in the study, and were precisely organized and grouped, fostering the conceptual categories and conclusions highlighted in the review. The analysis, in turn, referred to the purpose, objective, results and conclusion of the abstracts, with the aim of identifying the relevance and the relationship with the theme addressed. This way, the publications with the desired conceptual categorization were grouped to assess the similarity of the content. Then, the categories were analyzed, comparatively, by similarities and differences, for the construction of thematic contents.

DISCUSSION

Communicating is something from living together that makes it possible to share emotions, ideas, feelings and messages, which can cause different manifestations in people who, in turn, will respond based on their values, history, experience, culture and beliefs (OLIVEIRA, 2015).

In health care, it is necessary to relate and communicate in a careful and responsible way, seeking to translate, understand, understand and perceive the meaning of the message that the patient sends and, consequently,

identifying their needs and difficulties in all possible areas. Faced with such difficulties, one of the biggest obstacles these people face would be the possibility of enjoying a health service with resources to guarantee accessibility for the disabled. As a result, they are forced to depend on third parties to access health services, which makes them passive in their own citizenship and suppresses their privacy and independence when participating in a medical consultation (CASATE et al., 2005).

In order to adapt the care to the deaf patient, Decree n. 5626, of December 22, 2005, which regulated Law 10,436/02, also called Libras Law, a decree that established the mandatory presence of professionals trained in LIBRAS both in the Unified Health System (SUS) and in companies that hold the right to provide health services. However, the reality is far from the law, meaning that, in most cases, the deaf does not have access to what is right for them by the Federal Constitution (LEVINO et al., 2013).

Meetings between health professionals and deaf patients are often marked by barriers in communication. Thus, the study of the situation of individuals with hearing loss in the doctor-patient relationship is of great relevance, as it is useful for planning the professional's conduct. Highlighting and distinguishing the obstacles, desires and needs of the deaf patient contribute to a clearer and more empathic understanding by the medical professional, in the face of the unfavorable situation of communication (TEDESCO, 2013).

When faced with a negligent or unprepared health professional, the deaf patient will possibly inadequately understand how to take care of himself, and how to use medication, which can put his mental and/or physical health at risk (TEDESCO, 2013). In addition, superficial communication associated with

the lack of monitoring the development of the case gives doctors a false impression that they understand the patient, thus a possible inappropriate or unsatisfactory conduct (PEREIRA et al., 2020).

For the deaf, the means of communication used by the context that surrounds them is not presented as a resource that facilitates their exchange with society, but an obstacle that they need to overcome with difficulties to reach the social world effectively and also to guarantee their rights, above all, in health. As a result of these facts, it is necessary to propose that health professionals be trained and that the teaching of LIBRAS be fully implemented in undergraduate courses in Medicine, aiming at the necessary understanding for the humanized care of these patients (SOUZA, 2009).

Welcoming is based on the establishment of solidary and trusting relationships between professionals and people who seek the services, to solve their health problem, becoming an important aspect for the bond to occur, contributing to the resolution of the problem. The moment of reception in primary health care constitutes a potential scenario for ethical conflicts in the day-to-day of actions. In this context, meeting the health needs of people with disabilities means a challenge for professionals (NÓBREGA et al., 2012).

With the advent of modern science, the biomedical paradigm was established as the hegemonic discourse on deafness in the health domain, particularly in the technical-scientific and professional spheres. The deaf became an object of research in the health sciences and deafness came to be seen from an organic-biological point of view, classified into different degrees of hearing impairment. The representation of normality and abnormality, coined by scientific knowledge, made the hearing impaired object of science and of specialists, holders of the qualification and

mandate to describe, classify and intervene in the so-called deaf patient. From this point of view, sometimes, patients with deafness are considered abnormal, dependent on other people and incapable of providing for themselves (NÓBREGA et al., 2012).

Given the preponderance of biomedical studies on the interpretation of deaf patients, it is essential to understand the representations of a community of deaf users of sign language about their own deafness and about the health interventions aimed at them (BISOL, 2010).

The understanding that the deaf is recognized by a characteristic sociocultural identity is of great importance for the establishment of ideal communication and empathy, an identity that is shared by individuals who use sign language and do not see themselves as marked by a loss, but as members of a linguistic and cultural minority, possessing distinct norms, attitudes and values, and their own physical constitution (BISOL, 2010).

People with disabilities have been a relevant topic of discussions at a global and national level, in an attempt to bring social, educational and health equity, since the data reflect a significant amount of this portion of the population. In Brazil, according to the 2010 Census, there are 23.9% of the national population with some type of disability, and of these, 5.1% have deafness; and on a global scale, the deaf community totals about 360 million people (SOUZA et al., 2017).

There can often be obstacles in communication that compromise interaction and understanding between the hearing impaired patient and the professional, since the lack of established orality makes the deaf person disintegrated from the hearing society. The process of well-established communication in the field of health is essential to provide quality care, as it involves, in addition to its intrinsic aspects, listening in a welcoming

way, not only with the objective of passing on information for a conceptual understanding, but reaching the subjectivity of individuals (OLIVEIRA et al., 2015). In most cases, this communication takes place through verbal language, or even through writing and the use of gestures, and not through the Brazilian Sign Language (LIBRAS), the official language of the deaf population in Brazil. These tools do not allow a qualified listening to the health needs of this user, not even an adequate understanding of the health care offered by the service, which causes anguish and anxiety both in professionals and in the deaf person (TEDESCO, 2013).

In this context, the medical professional must be aware of the difficulties of the deaf in learning the oral language because they have LIBRAS as their first language, knowing that the construction of knowledge is done in a different way for each of the language modalities. An enlightened understanding of the deaf patient's needs needs to go beyond the current biomedical model and value the different nuances that make up these patients (biopsychosocial and cultural) (OLIVEIRA et al., 2015).

Observational studies are important for a solid understanding of the perspective of deaf patients to occur, with the aim of clarifying for the health professional the best way to communicate them. A descriptive observational study was carried out in the city of Maringá with 181 participants: medical professionals (n = 46), fifth and sixth year medical students (n = 54) and deaf individuals (n = 81). We sought to characterize the care provided to the deaf, from the point of view of medical professionals, medical interns and the users themselves, as well as to discuss the strategies developed in the dialogue and doctor-patient interaction and the means to improve medical practice. As for the difficulties encountered during care, for

58.7% (37) of physicians and 51.2% (22) of interns, the greatest difficulty reported was to explain information about the disease, such as a therapeutic plan and general clarifications. Regarding the difficulty in understanding the other, 33.3% (21) of the doctors and 34.9% (15) of the interns reported difficulties in understanding the patient, and 38.1% (37) of the deaf stated that they have difficulty understand the medical/internal professional. Other difficulties were mentioned by the deaf, 55.5% (45) stopped going to the doctor for fear of not being understood, causing discomfort or anguish. Still, 72.8% (59) mentioned the custom of taking companions to the medical appointment (PEREIRA et al., 2020).

Another study aimed to hear from oral deaf, bilingual or who only communicate through sign language, which factors can make communication with the doctor inappropriate, as well as suggestions to improve this communication. The place where the interviews were carried out was the Instituto Nacional de Educação de Surdos (INES), and 18 deaf people participated in this study, eight men and 10 women, aged between 22 and 58 years, and 10 communicate by Libras (five men and five women), four bilingual (two men and two women), and four oral (one man and three women). Deaf patients reported encountering conflicting perceptions between physicians and patients about hearing impairment and what constitutes effective communication (lip reading, writing). They also mentioned insecurity regarding medications and communication problems during the physical examination and procedures, as well as difficulties in interacting with the team (including the administrative part), and also in the waiting room. The percentage of negative evaluations of the meeting with health professionals represented 57% of the responses of the oral deaf people; 62% among bilinguals; and 61%

in the group of deaf people who communicate through sign language (COSTA et al., 2009).

It is observed that some professionals usually do not understand the particularities of the deaf. Therefore, to avoid adversities and mistakes in the transmission of information, the medical professional must: seek to speak while looking at the patient, without writing while speaking; having a lit face, and speaking slowly and clearly; avoid speaking long words; knowing that the use of a mustache or beard can make lip reading difficult; articulate words well; write, make facial expression, mime; use simple words and simplify terms; explain before and sometimes during a procedure; write the recipe step by step: hour by hour – 1 hour clock at night; 2 o'clock in the afternoon; explain what the drug is for; write light Portuguese; Have patience. Writing while talking to the patient, calling him out loud from another room and being impatient when needing to explain the prescribed drugs better and slower are attitudes that demonstrate professional unpreparedness. This goes beyond the lack of knowledge of LIBRAS and permeates the misunderstanding of the deaf person's identity and the cultural factors that characterize their community (PEREIRA et al., 2020; COSTA et al., 2009).

The presence of the Libras interpreter in health services is already provided for in Law No. 10,098, of December 19, 2012, known as the Accessibility Law, in Chapter VII, although apparently it has not been complied with. It is important to highlight that the presence of a third person in meetings between patients who use sign language and health professionals who do not know it, can facilitate communication, but can also lead to a lack of privacy, and even autonomy on the part of the patients. Deaf people who only communicate through LIBRAS face the same difficulties as foreigners who do not speak Portuguese. They can be considered foreigners in their own

country, although LIBRAS has already been officially recognized. As for writing, despite being a facilitating factor in communication with oralized deaf patients, it is of little help for pre-linguistic deaf people, that is, those who became deaf before the acquisition of oral language (COSTA et al., 2009).

Accessibility is a vital pillar for achieving quality and equity in health services. Functional accessibility, on the other hand, offers timely and adequate services to the needs of the population (UNGLERT, 1990). Thus, it is necessary to spread knowledge about LIBRAS among students of health courses, to contribute to the training of professionals able to understand and help the needs of people who use it as their first language.

Although the teaching of LIBRAS has been offered optionally for most courses in higher education since the last ten years, we see little expression of this knowledge among health professionals. There are proposals for the implementation of mandatory teaching of Libras in early childhood education and elementary school (such as Senate Bill 14/2007), which would be very enriching in the cultural education of both deaf and hearing children (MARQUES et al, 2013). Such an implementation would also bring positive changes in relation to the current scenario, since in higher education the student could program their basic knowledge with more advanced and specific courses in Libras for health, in the case of professionals undergoing training in the area.

As much as it is known that some changes are more difficult and slower, proposals can be put into practice immediately, such as taking the discussion about communication with non-verbal patients to health practice spaces and the academic environment. It is also suggested the study of scientific publications in order to develop communication skills with deaf patients and to understand their

perspective. From this, the patient and attentive professional, interested in understanding and being understood by his patient, will be able to have good communication (COSTA et al., 2009).

It is common for the deaf population to have less education than the general population, therefore, they need more attention and care when using technical terms, avoiding words that can lead to confusion with the need to use legible handwriting. It is necessary to remember that deaf people communicate using LIBRAS, which has a grammar and vocabulary that is different from the Portuguese language (CARDOSO et al, 2006). When there is the presence of a family member or a companion of the deaf user, he is an important facilitator who serves as a “translator” for the service to occur. And, by depending on other people to access health services and information, the citizenship of the deaf is impaired (CASATE et al, 2005).

FINAL CONSIDERATIONS

In this scenario, the article highlighted and supported the premise that the problem faced by the deaf in the doctor-patient relationship is not organic, but social, cultural and educational, due to the fact that most health professionals are not prepared to deal with their situation. situation and thus adequately meet their demands. As for other problems faced, there are the non-compliance with the mandatory presence of the interpreter, and the insufficiency or absence of LIBRAS learning, which must be better imposed, both at school and higher levels. It is noteworthy that depending only on the interpreter or companion ends up generating discomfort or embarrassment for the non-verbal patient, since their intimacy and doctor-patient confidentiality are weakened by the presence of a spectator. Finally, the government must be more concerned with the health

systems in carrying out the training of health professionals: public awareness campaigns with accessibility must be stimulated together with the biopsychosocial care of this patient. Thus, small details can lead to a more humanized care and, consequently, contribute to the reduction of the social marginalization of which the deaf is in this society structured for the hearing individual.

It is essential to emphasize the need to carry out studies related to the care of deaf patients in the medical field, given the reduced number of scientific publications on this topic in Brazil. Observational studies and reviews are essential for a better understanding of this problem, demonstrating the relevance of this study in the medical and scientific scope.

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