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Challenges and Communication Strategies in Pediatric Care for Hearing Children of Deaf Parents

Desafios e Estratégias de Comunicação no Atendimento Pediátrico a Crianças Ouvintes Filhas de Pais Surdos

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ABSTRACT

Objective: to understand the challenges and possibilities in medical care between pediatricians and deaf parents who use sign language in the care of children's health.

Methods: qualitative and exploratory cross-sectional research was based on semi-structured interviews with pediatricians and a CODA family.

Results: the study indicated that the lack of training in LIBRAS (Brazilian Sign Language) compromises direct communication between doctors and deaf parents, generating dependence on interpreters or family members to mediate the interaction. This scenario limits parental autonomy and can affect the accuracy of the information transmitted. Pediatricians recognized the need for the inclusion of LIBRAS in medical curricula and pointed to the use of assistive techno-

Final considerations: the training of professionals in LIBRAS and the implementation of public policies focused on accessibility are fundamental to guaranteeing more inclusive and humanized care.

Keywords: LIBRAS; CODA; Medical care; Pediatrics; Deafness.

RESUMO

Objetivo: compreender os desafios e as possibilidades no atendimento médico entre pediatras e pais surdos sinalizantes no cuidado da saúde da criança.

Métodos: abordagem qualitativa e exploratória do tipo transversal, baseou-se em entrevistas semiestruturadas com médicos pediatras e uma família CODA.

Resultados: o estudo indicou que a ausência de formação em LIBRAS compromete a comunicação direta entre médicos e pais surdos, gerando dependência de intérpretes ou familiares para mediar a interação. Esse cenário limita a autonomia dos pais e pode afetar a precisão das informações transmitidas. Os pediatras reconheceram a necessidade da inclusão da LIBRAS nos currículos médicos e apontaram o uso de tecnologias assistivas como alternativa para melhorar a acessibilidade.

Considerações finais: a capacitação dos profissionais em LIBRAS e a implementação de políticas públicas voltadas à acessibilidade são fundamentais para garantir um atendimento mais inclusivo e humanizado.

Descritores: LIBRAS; CODA; Atendimento médico; Pediatria; Surdez.

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INTRODUCTION

The deaf community constitutes a significant segment of the global population, with distinctive socioeconomic and cultural characteristics. According to data from the Brazilian Institute of Geography and Statistics (IBGE), Brazil has a considerable population of deaf individuals. The 2022 Demographic Census recorded approximately 10 million Brazilians reporting some degree of hearing impairment, of whom 2.7 million were classified as profoundly deaf.[1]

The deaf community is characterized by a diversity of experiences and communication practices. Deaf individuals may use LIBRAS as their primary mode of interaction (signers), communicate predominantly through oral language (oralized deaf), or function bilingually, alternating between LIBRAS and spoken language. Additionally, some employ total communication, combining multiple modalities such as signs, speech, visual support, and gestures, while others use alternative forms of communication not restricted to these models. Although oral language users, the latter group requires communication accessibility tailored to their specific needs, as full comprehension of speech depends on orofacial reading (lip-reading) and written support (subtitles).[2]

Nonetheless, these individuals face communication barriers on a daily basis owing to the general population's lack of familiarity with LIBRAS, which frequently distances deaf people from educational opportunities, employment, and adequate health services.[3] The absence of qualified interpreters and accessible materials can limit access to essential information, underscoring that the promotion of interpreting services, the provision of adapted educational materials, and digital accessibility are essential measures to dismantle such barriers.

The deaf community presents great cultural, linguistic and identity diversity, bringing different perspectives and social experiences that enrich Brazilian cultural plurality. The process by which deaf culture and identity are consolidated is essentially plural, as it recognizes the differences that exist between people and, because they are human, each one is unique, carrying multiple social and cultural identities. From this diversity emerge different ways of existing within the same social system, which shelters a wide variety of behaviors. The current time has as its fundamental value the full expression of all freedoms, referring to the idea of multiverses contained in a single universe. It is precisely in this plural scenario that it becomes impossible to repeat the practices of oppression, segregation and exclusion suffered by the deaf community in past centuries[4].

Another relevant point is the presence of Children of Deaf Adults (CODA), which in Portuguese means "child of deaf parents". It was chosen to use the acronym CODA, because in Brazil no other acronyms or words are created that name these subjects specifically. Therefore, the form used in the United States of America, Latin America, Europe and other countries in Asia is maintained. A survey on people born to deaf parents revealed that in Brazil there are about 5.7 million people who are deaf or have some type of hearing impairment[5].

Although Brazil recognizes LIBRAS as a right of the deaf community, it is important not to associate deafness exclusively with its use. Several authors demonstrate that deaf identities are multiple and multifaceted, covering not only signers, but also oral deaf people, bilingual people, users of total communication or other modalities of expression6. This plurality reinforces the need for accessibility policies and practices that contemplate the different ways of being deaf, avoiding a monolithic and excluding view.

Thus, CODA children face additional challenges when they have to act as interpreters for their deaf parents, which can cause stress and impair their emotional development[5]. This situation requires an adaptation of health services to meet the needs of this population in a more humanized and inclusive way[7,8].

Family dynamics play a crucial role in the development and well-being of the child from the earliest stages of their life. When it comes to medical care services, children of deaf parents face a special difficulty in pediatric care, in which health professionals play a fundamental role in promoting health and in the care of children. However, a particular and enriching scenario presents itself when the CODA is the patient in question, since these children experience an adverse experience of the reality of most children of hearing parents, remaining immersed and divided into two cultures, two languages, with different responses to different stimuli[9].

This situation challenges traditional patterns of communication and interaction in the provision of medical care, requiring a sensitive and adapted approach to ensure mutual understanding and quality of care, highlighting the importance of cultural sensitivity, effective communication, and respect for family diversity[9].

In this context, CODA children, as subjects of rights, have legal guarantees of access and quality care in health institutions. This right has been guaranteed since the Federal Constitution of 1988, which considers health as an essential factor for the realization of fundamental rights and advocates the equality of all before the law. In addition, Law No. 10,436 of 2002 and the Brazilian Inclusion Law of 2015 (LBI) reinforce the right to health guaranteed by the State, in accordance with society, in addition to ensuring the right to clear and objective communication[10,11]. It is important to note that without effective communication between doctor and patient, errors can occur in both diagnosis and treatment.

In this sense, Decree No. 5626, of 2005, complements these laws by guaranteeing the right to health for deaf patients, even if CODA children are hearing patients. These children often depend on their parents to communicate with health professionals, making this legislation indispensable. Article 25 of the Decree establishes that the Unified Health System (SUS) must ensure the full inclusion of deaf people in all spheres of social life, including comprehensive health care[12].

However, in practice, this guarantee often does not materialize. Many institutions, both public and private, do not offer qualified professionals to communicate with deaf patients. The competence of the public health system should be seen as a reflection of inclusion and welcoming policies, with communication being a key factor. The lack of clear communication harms the bond between health professionals and deaf patients, compromising the quality of care[8].

In view of this, it is emphasized that the care of CODA children requires specific care, especially due to the communicational complexity involved in the interaction between health professionals and deaf parents.

In addition, Guimarães et al.[8], in their work, identified that the cognitive development of CODA children, especially with regard to language, can be affected by the early responsibility of mediating communication between their parents and society, which directly interferes with the emotional and social development of these children, highlighting the need for a more attentive and inclusive look on the part of health professionals.

Therefore, it is evident that, to ensure excellent service, it is essential that health professionals are trained to communicate in LIBRAS. The lack of this skill not only compromises humanized care, but also generates barriers that directly affect the well-being of patients and their families. Thus, strengthening effective communication between doctors and deaf patients or CODA is a crucial issue to promote inclusion and quality in health services.

This situation reflects the need for more research in this area in order to identify barriers and propose solutions that ensure adequate care for deaf parents and their children in order to avoid possible speech and language difficulties, as well as social exclusion of deaf people and children of deaf people. In this context, the following problematization is presented: what are the main difficulties and possibilities in the care of hearing children, daughters of deaf parents (CODA) at the Integrated Health Care Center (CAIS) of Itumbiara-GO and at the José Gomes da Rocha Outpatient Clinic?

Finally, the objectives of this research were: to understand the challenges and possibilities in medical care among pediatricians and deaf parents in the municipality of Itumbiara-GO, with regard to child health care; identify the communication barriers that exist between pediatricians, CODA patients and their families; and to identify the training of pediatricians who work at the Integrated Health Care Center (CAIS) and at the José Gomes da Rocha Outpatient Clinic.

METHODS

This study employed a qualitative, exploratory, cross-sectional design, enabling data collection in the participants' natural environment and providing in-depth analysis from the perspective of those involved.[13,14]

Data collection was conducted through semi-structured interviews with five pediatricians who had previously provided care to hearing children of deaf parents. The interviews were held at the Integrated Health Care Center (CAIS) and the José Gomes da Rocha Outpatient Clinic—the settings where participants provide medical care—both located in the municipality of Itumbiara, Goiás.

According to IBGE, in 2022 the city had an estimated 107,970 inhabitants and the demographic density was 44.12 inhabitants per square kilometer, the GDP per capita was BRL 49,832.28 and the Human Development Index (HDI) was 0.752 in 2010.

In accordance with the ethical guidelines for research involving human beings, this study was submitted to the Research Ethics Committee (REC) and approved under CAAE process 74544623.7.0000.5080. All participants were informed about the objectives, risks and benefits of the research, ensuring the confidentiality of their information. Consent for participation was formalized by signing the Informed Consent Form (ICF), available in two copies, one for the participant and the other for the researchers.

Participants were selected through face-to-face contact, after authorization from the health institutions involved. Five pediatricians were interviewed. The inclusion criteria included pediatricians working in the Unified Health System (SUS) in Itumbiara-GO, residing in the city and who signed the ICF.

The interviews were audio-recorded and addressed issues related to knowledge and training in LIBRAS, communication difficulties in the care of CODA patients and suggestions for improving medical care. The questions included topics such as professional experience with deaf patients, training in LIBRAS and the impact of the insertion of the discipline in medical training.

Four categories of analysis were established for the interviews with the pediatricians: (a) characterization of the professionals, (b) knowledge and training in LIBRAS, (c) challenges in communication and strategies adopted, and (d) suggestions for improving care.

RESULTS

The participants included in the study totaled five pediatricians. In order to protect the identity of the interviewees, their statements were identified by the letter P (pediatrician), numbered from 1 to 5, with P1 referring to the first participant and P5 to the last.

To analyze the data collected, they were divided into four thematic categories, described below.

The average time of professional training of the participants at the time of data collection was approximately 25 years.

None of the participants received training in LIBRAS during their medical studies, but all reported providing care to deaf people or hearing children of deaf parents in the academic environment, with the help of an interpreter.

All pediatricians stated that knowledge in LIBRAS was not part of their academic curricula, P3 reports that: "*on my own I learned a little Libras and I can speak something, but on my own*". However, the other professionals said they had not sought additional training in the area. P1 stated that the reason why he never sought additional knowledge was due to: "*over-work, not that I don't think it's important, but over-work I never did*", corroborating P4 in his statement: "*I always wanted to take a sign language course, I just didn't have the opportunity*".

The lack of skills in LIBRAS was recognized by professionals as an obstacle to inclusive and effective care, according to P2: "*The course could include everyone, which it does not have (currently)*", reinforcing the importance of including the discipline of LIBRAS in medical courses and pointing out that this skill is essential for a more humanized service, allowing direct communication with deaf patients, without the need for intermediaries.

The difficulty reported by the professionals may not be related only to the communication of the deaf parents, but also to the limitation of the professionals themselves in understanding alternative communicative strategies used by the families.

Communication with CODA patients and their families was described as a considerable challenge due to the lack of mastery of LIBRAS. In a report of one of his experiences, P1 said that: "*The child spoke the symptoms, but the parents could not pass on the information they should have given, needing a person who understood the family's logistics to help with the consultation*", while P4 declared: "*I had a case in which the child behaved like an adult... the child guiding*"

To circumvent this barrier, pediatricians often rely on family members or interpreters to translate medical information, diagnoses, and treatment guidelines. P5 reports that in his consultations: "*I had no difficulty because I always had an interpreter... But it's not the same thing.*" However, when interpreters are not available, other approaches are used, as informed by P2: "*I communicated through writing and by mouth... I spoke slowly for her to read my lips... I felt ashamed.*"

The doctors suggested the mandatory inclusion of LIBRAS in medical curricula and in other places, as stated by P3: "*I think it is extremely important to add LIBRAS not only in health courses, but everywhere.*", highlighting that this measure could improve communication and ensure more effective care for deaf patients and CODA.

In addition, as stated by P2: "*Having an app or someone prepared in the hospital*" could improve care, indicating the potential use of assistive technologies and the training of professionals, which could help facilitate interaction with patients who use LIBRAS. In P5's view: "*You have to try to study, at the same time, the basics*", and these improvements are essential to make public health more inclusive and egalitarian.

In addition, P5 warns about the unpredictability of these appointments: "*You can deal with it at any time and you may not have an interpreter to help you*". This perception supports the idea that training in LIBRAS should not be optional, but essential to ensure equity in access to health.

Therefore, the interviewees believe that the personal search for knowledge about inclusive communication is fundamental for all health professionals, allowing them to adapt to the individual needs of each patient and ensure a more complete and compassionate medical care in all situations.

DISCUSSION

The findings of this study pertain specifically to care interactions involving deaf parents who communicate through LIBRAS. The physicians reported having had no exposure to LIBRAS during their undergraduate medical training, a finding consistent with the current reality of most medical curricula.

In light of this gap, one proposed solution is the use of qualified interpreters during consultations, which is considered essential for effective communication between physicians and deaf patients, reducing the likelihood of misdiagnosis and inappropriate treatment while upholding the deaf person's right to health.[15,16] However, interpreter availability remains unrealized in many healthcare settings, particularly in emergency services, making this an impractical alternative in numerous contexts.

Furthermore, reliance on interpreters may compromise patient autonomy and raise concerns regarding confidentiality and informational accuracy during clinical encounters. Deaf patients frequently report dissatisfaction in consultations requiring interpreter mediation, citing discomfort and limitations in direct communication with the attending physician.[17]

From this perspective, the development of assistive technologies for LIBRAS represents a potential strategy to enhance accessibility and inclusion for the deaf community.[18] Notable examples include the VLIBRAS system and Google Translate with LIBRAS support, which convert written text into sign language intelligible to deaf users. However, these technologies remain unable to adequately capture the full range of facial expressions and body language that are integral to conveying meaning in LIBRAS,18 thus limiting the quality of interaction. Consequently, while these tools hold considerable promise, further development is required to achieve communicative equivalence with direct Brazilian Sign Language interaction.

On the other hand, the deaf person would have better interaction with the professional, reporting greater comfort, acceptance and a feeling of appreciation as a citizen, fulfilling their obligations and duties, if the doctor knew the Brazilian sign language[19]. This situation reinforces the notion that the use of LIBRAS by health professionals is a matter of accessibility and respect for the rights of the deaf, which should be promoted both by medical training and by public health policies[20].

The findings of this research reinforce the need to include content related to inclusive communication and LIBRAS in medical training and continuing education programs. In addition, they highlight the importance of expanding access to interpreters, the development of assistive technologies and the implementation of institutional protocols that favor effective communication between health professionals, deaf parents and hearing children.

This study has some limitations, including the small number of participants, the geographical delimitation restricted to the municipality of Itumbiara-GO, and the fact that it is performed exclusively in specific health services. In addition, as this is a qualitative research, the results cannot be generalized to the entire population of health professionals and CODA families, although they allow relevant reflections on communication barriers in pediatric care.

In view of these findings, it is essential that new research explores the effectiveness of different methods of teaching LIBRAS to health professionals, in order to verify which approaches would be more viable for medical practice, enabling the adequate training of doctors, reducing the dependence of deaf patients on interpreters, software and family members, ensuring that deaf parents can effectively participate in their children's consultation.

CONCLUSION

The findings of this study demonstrate that the absence of LIBRAS training among pediatricians constitutes one of the principal barriers to the inclusion and humanized care of deaf parents and their hearing children. The lack of this competency compromises direct communication, generating dependence on interpreters or family members as intermediaries, which may reduce the autonomy of CODA families and increase the risk of miscommunication during medical consultations.

The pediatricians interviewed acknowledged the importance of integrating LIBRAS as a formal discipline within medical education and identified the use of interpreters and assistive technologies as possible strategies to mitigate communication barriers. However, such tools continue to present limitations in capturing the full expressiveness of LIBRAS, reinforcing the need for a broader, more humanized approach to health professional training.

Furthermore, the implementation of public policies that promote LIBRAS training for health professionals is essential to guarantee inclusive, equitable care that upholds the rights of the deaf community. Expanding interpreter access within health services and advancing assistive technologies may serve as complementary strategies to enhance the quality of communication and care delivered to this population.

Given this context, it is imperative that future research investigate effective methodologies for teaching LIBRAS within health professional curricula and evaluate the impact of different communication strategies on the experiences of deaf patients and their families. Only through concrete and sustained actions will it be possible to reduce language barriers and ensure a more accessible and humanized service for all.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHOR CONTRIBUTIONS

Guimarães MEB, Ferreira LAV, Capatti LOM, Leão KR, Oliveira PRP, Moura MRS, Rodrigues RP participated in conceptualization, methodology, formal analysis, investigation, and writing – original draft preparation.

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