

WHEN HEALTHCARE DOESN'T SPEAK SIGN LANGUAGE: (AUTO)BIOGRAPHICAL NARRATIVES FROM DEAF PEOPLE ABOUT THE COVID-19 PANDEMIC

*Quando a saúde não fala libras: narrativas (auto)biográficas de pessoas
surdas sobre a pandemia da COVID-19*

*Quando la salud no habla libras: narrativas (auto)biográficas de
personas sordas sobre la pandemia de COVID-19*

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ABSTRACT

The COVID-19 pandemic exacerbated historically existing inequalities faced by the deaf community, intensifying communication difficulties in accessing healthcare services and compromising their right to information and care. This study aimed to understand the impacts of the pandemic on the experience of deaf people in relation to healthcare. This is a qualitative study, based on an (auto)biographical approach. Seven deaf adults who are speakers of Libras (Brazilian Sign Language) and/or oralized participated, interviewed remotely. The data were analyzed through thematic analysis of the narratives. The results highlighted communication difficulties related to the reduced number of healthcare professionals able to communicate in Libras, the scarcity of Libras interpreters in healthcare services, the use of masks, and restrictions on the presence of companions, compromising autonomy, privacy, and safety during care. It is concluded that guaranteeing linguistic and communicational accessibility is essential for the effective realization of the right to health for the deaf population.

Keywords: COVID-19. Persons with hearing disabilities. Sign language.

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RESUMO

A pandemia da Covid-19 agravou desigualdades historicamente vivenciadas pela comunidade surda, intensificando dificuldades de comunicação no acesso aos serviços de saúde e comprometendo o direito à informação e ao cuidado. Este estudo objetivou compreender os impactos da pandemia na experiência de pessoas surdas em relação ao atendimento em saúde. Trata-se de uma pesquisa qualitativa, fundamentada na abordagem (auto)biográfica. Participaram sete adultos surdos falantes de Libras e/ou oralizados, entrevistados remotamente. Os dados foram analisados por meio da análise temática das narrativas. Os resultados evidenciaram dificuldades comunicacionais relacionadas ao número reduzido de profissionais da saúde capazes de se comunicar em Libras, à escassez de intérpretes de Libras nos serviços de saúde, ao uso de máscaras e às restrições à presença de acompanhantes, comprometendo a autonomia, a privacidade e a segurança durante o atendimento. Conclui-se que a garantia da acessibilidade linguística e comunicacional é essencial para a efetivação do direito à saúde da população surda.

Palavras-chave: COVID-19. Pessoas com surdez. Língua de sinais.

RESUMEN

La pandemia de la COVID-19 agravó las desigualdades históricamente experimentadas por la comunidad sorda, intensificando las dificultades de comunicación en el acceso a los servicios de salud y comprometiendo el derecho a la información y a la atención sanitaria. Este estudio tuvo como objetivo comprender los impactos de la pandemia en la experiencia de las personas sordas en relación con la atención en salud. Se trata de una investigación cualitativa, fundamentada en el enfoque (auto)biográfico. Participaron siete adultos sordos usuarios de la Lengua de Señas Brasileña (Libras) y/o oralizados, entrevistados de forma remota. Los datos se analizaron mediante el análisis temático de las narrativas. Los resultados evidenciaron dificultades comunicativas relacionadas con el número reducido de profesionales de la salud capaces de comunicarse en Libras, la escasez de intérpretes de Libras en los servicios de salud, el uso de mascarillas y las restricciones a la presencia de acompañantes, comprometiendo la autonomía, la privacidad y la seguridad durante la atención. Se concluye que garantizar la accesibilidad lingüística y comunicacional es fundamental para hacer efectivo el derecho a la salud de la población sorda.

Palabras clave: COVID-19. Personas con deficiencia auditiva. Lengua de signos.

INTRODUCTION

COVID-19 (Coronavirus Disease 2019) was characterized as a pandemic by the World Health Organization (WHO) on March 11, 2020, due to the high transmission rate of the virus and its global spread. In the context of the COVID-19 pandemic, the inequalities historically experienced by the deaf population worsened, especially regarding communication accessibility in social, educational, and health contexts. This scenario amplified situations of vulnerability, compromising access to reliable and accessible information during a period marked by the constant updating of health guidelines¹. Among the main challenges are the absence of Brazilian Sign Language (Libras) and subtitles in official broadcasts on open television², the limitations of automatic subtitles on digital platforms, such as semantic inaccuracies, lack of synchronization and inadequacy to the content presented³⁻⁴, in addition to the reduced number of health professionals able to communicate in Libras and the scarcity of Libras/Portuguese Language translators and interpreters (TILSP) in health services, compromising access to information, autonomy and the quality of care provided to deaf people⁵.

It is important to highlight that the use of face masks, a measure adopted to contain the spread of the SARS-CoV-2 virus, has compromised essential elements of communication for the deaf population. Masks can obstruct the visualization of facial expressions, non-manual markers of a grammatical nature in Libras (Brazilian Sign Language), hinder lip-reading, and attenuate high-frequency sounds, further impairing communication in face-to-face contexts⁶.

In the case of deaf people who use ^[i]Libras (Brazilian Sign Language), the scarcity of accessible information in sign language about Covid-19 represented an additional risk, compromising their understanding of prevention and care measures⁸⁻⁹. Given this scenario, this study aimed to identify and analyze the needs of deaf people regarding access to health services in the face of the pandemic and the situations it imposed.

METHOD

This study is an excerpt from the results of the ^[ii]first author's doctoral research, developed under the guidance of the second researcher, whose purpose was to understand and analyze the needs of deaf people related to access to health, social isolation, and remote schooling in the context of the Covid-19 pandemic. It is a qualitative research study, grounded in an (auto)biographical perspective, aiming to understand the experiences lived by deaf people and the meanings they attribute to their own trajectories in the pandemic context.

(Auto)biographical narratives constitute a space of production in which the meanings attributed by people to lived experiences and the social and cultural dimensions that permeate them intersect. In narrating, each person mobilizes references from the context in which they are embedded, articulating aspects of their personal history with the social conditions that permeate their existence. In this way, narrative construction makes visible the plot elaborated from the relationship with the world and can trigger a transformative process, by enabling the elaboration of different meanings and ways of being and acting. From this perspective, qualitative research proved relevant by enabling the understanding of the interpretations constructed by the participants. Thus, (auto)biographical narratives are not limited to the recording of events, but encompass the processes by which people interpret, organize, and attribute meaning to their experiences, articulating personal and social dimensions¹⁰⁻¹².

The study was submitted to and approved by the Ethics Committee for Research in Human and Social Sciences of the Universidade Estadual de Campinas (UNICAMP), under the Certificate of Presentation and Ethical Appraisal (CAAE) No. 53199221.00000.8142 and opinion No. 5.233.075. Ethical procedures regarding voluntary participation, participant consent, and authorization for recording and using images were observed, as stipulated in the protocol approved by the Ethics Committee.

Given the presentation of the methodological design adopted, the subsequent section will address the procedures used to define and select the deaf individuals who participated in the research.

Participants

The study group was formed through interpersonal referrals, drawing from the researcher's and her advisor's network of deaf people. This strategy made it possible to identify those who met the pre-established criteria and were able to participate in remotely conducted interviews.

Seven deaf adults, residing in different regions of Brazil, participated in the investigation. The inclusion criteria were: (i) age 18 years or older; (ii) moderate to profound hearing loss¹³, of congenital origin or acquired in early childhood; (iii) residing in any region of Brazil; (iv) communicating in Libras (Brazilian Sign Language) and/or in spoken Portuguese; (v) using or not using electronic hearing aids (AADs), such as hearing aids and/or cochlear implants; (vi) having access to and autonomy to use digital applications with video calling capabilities; (vii) being literate and demonstrating comprehension of written Portuguese; (viii) formally agreeing to participate in the research by signing the Informed Consent Form and the Image Use Authorization Form; and (ix) having a history of confirmed diagnosis of Covid-19 infection, with a positive result on a specific test.

[i] In this work, we use the expression "speaking Libras" in accordance with the understanding that Libras constitutes a natural language, endowed with its own grammar and full linguistic status. As discussed by Gesser⁷, the recognition of Libras as a language implies overcoming restrictive conceptions that associate it exclusively with gesture or mimicry, legitimizing the use of verbs traditionally employed for oral languages, such as to speak, in the sense of communicating linguistically in Libras, regardless of its visual-spatial modality.

[ii] Sígolo C. (Auto)biographical narratives of Deaf people about the Covid-19 pandemic: reflections from Deaf perspectives [doctoral thesis]. Campinas (SP): State University of Campinas; 2024.

The following exclusion criteria were established: (i) age under 18 years; (ii) inability or refusal to participate in the research; and (iii) failure to meet the established inclusion criteria.

The study included seven adult participants with congenital or childhood-acquired deafness and severe to profound hearing loss. All spoke Brazilian Sign Language (Libras) and/or spoken Portuguese, were literate in Portuguese, and demonstrated autonomy in using the digital technologies necessary for conducting video conference interviews. In addition, they held higher education degrees, worked in various fields, and had a history of COVID-19 infection.

Although not a pre-established inclusion criterion, all participants were teachers and/or held leadership positions and worked in the deaf community. This characteristic was considered in the interpretation of the results, since their professional and community experiences were dimensions present in their narratives.

Procedures for collecting and presenting narratives

The interviews were conducted between March 2022 and January 2024. Considering the context of the Covid-19 pandemic during part of the research period and the participants' residence in different locations across the country, it was decided to conduct the interviews via videoconference, using the *Google Meet platform*.

For the production of the narratives, a semi-structured interview script was developed (Appendix 1), constructed based on the research objectives and organized into topics related to the experiences lived by the participants in the context of the pandemic. The script included questions related to health experiences, social isolation, and remote schooling, allowing participants to freely develop the aspects they considered relevant in their trajectories.

The semi-structured script was used as a guiding instrument for the interview, not to restrict or standardize the narratives. The questions served as triggers for the production of the accounts, allowing each participant to organize their experiences according to their own memories, perceptions, and forms of meaning-making.

The interviews were conducted by the researcher in Libras (Brazilian Sign Language) or in Portuguese, orally, according to the language of comfort and communication preference of each participant. All interviews were video-recorded, with the participants' permission, and had an average duration of 60 minutes.

After conducting the interviews, the narratives produced in Libras (Brazilian Sign Language) were translated into written Portuguese by the researcher herself. Subsequently, the translated material was submitted to a professional translator (TILSP) to verify the correspondence between the content produced in Libras and its presentation in written Portuguese.

Subsequently, the accounts were sent to the respective participants for review and validation. Participants were able to confirm the presented content, clarify information, and request adjustments when necessary. This procedure aimed to preserve the meanings attributed to the narrated experiences and to ensure greater fidelity to the process of translating and presenting the narratives in written Portuguese.

The *corpus* of analysis consisted of the seven narratives produced in the interviews. The data were analyzed using Content Analysis¹⁴, articulated with the assumptions of (auto)biographical research. The choice of this procedure made it possible to organize and systematize the material produced, identify units of meaning, establish thematic categories, and interpret the contents present in the narratives in articulation with the objectives of the study and the adopted theoretical framework.

The categorization considered both the recurrence of the content and its relevance to understanding the phenomenon under investigation. Thus, the presence of a particular aspect in a single narrative was not disregarded when it presented interpretative relevance to the study's objectives. Similarly, the recurrence of a

theme among the participants was not taken in isolation as an indicator of its importance, but was considered in conjunction with the context and the meanings attributed to the narrated experiences.

The interpretation considered the narratives in their individual and collective dimensions. Therefore, the accounts were analyzed both from the particular experiences of each participant and from the convergences and divergences identified among the seven narratives. The linguistic, social, educational, and professional conditions that influenced the reported experiences were considered, as well as the strategies employed by the participants in response to the situations experienced during the pandemic.

To avoid fragmentation of the accounts, the excerpts selected for presentation of the results were analyzed in relation to the broader context of each narrative. The selection of excerpts considered their relevance to the study's objectives and their ability to highlight the meanings attributed by the participants to the experiences analyzed. In this way, the results were not presented solely based on the frequency of content, but also considering the uniqueness of the trajectories and the meanings constructed by the participants.

The use of Content Analysis¹⁴ in conjunction with the (auto)biographical perspective¹⁰⁻¹² thus made it possible to systematize the seven narratives without reducing the participants' experiences to an exclusively quantitative analysis or one based on the frequency of occurrence of the content. The analysis sought to understand how deaf people gave meaning to their experiences during the pandemic, considering both the elements shared between the narratives and the particularities of each trajectory.

RESULTS

The characterization of the sample of participants is described in *Table 1*. To guarantee confidentiality and preserve the identity of the respondents, fictitious names were assigned, chosen in reference to historical references of the international deaf and deafblind movement¹⁵.

Table 1 - Characterization of the research participants.

Number	Fictitious name	Biological sex	Age	Degree of hearing loss	Language of communication preferential	Education	Profession
1	Ferdinand Berthier	Masculine	40	Deep	Brazilian Sign Language	Master's degree	University Professor
2	Helen Keller	Feminine	40	Deep	Brazilian Sign Language and Portuguese	Superior	Veterinary Doctor
3	Louise Walser	Feminine	42	Deep	Pounds	Post-Graduation	University Professor
4	Jeanne Stuart	Feminine	42	Deep	Pounds	Post-Graduation	University Professor
5	Annie Cannon	Feminine	38	Deep	Pounds	Post-Graduation	Teacher
6	Gertrude Caroline Ederle	Feminine	55	Deep	Pounds	PhD	University Professor
7	Pierre Desloges	Masculine	50	Deep	Pounds	PhD	University Professor

Source: Prepared by the authors (2026)

Regarding the analysis of excerpts from the (auto)biographical narratives of the deaf respondents, it was evident that the conditions of greater vulnerability during the pandemic due to the scarce information in sign

language and the obstacles encountered by deaf people in accessing healthcare during that period were made explicit in the accounts obtained from all seven respondents.

At the beginning of the pandemic, between March and April 2020, I started experiencing muscle pain, back pain, lower back pain, weakness, joint pain, and allergies. Since these symptoms weren't associated with Covid-19 at the time, I didn't suspect anything. I went to the doctor, who prescribed only muscle relaxants, saying it wasn't Covid. Without improvement, I went to the hospital a month later. They prescribed medications from the protocol at the time, such as deworming medication and anti-inflammatories, but I continued to feel unwell. I had a blood test that indicated an infection, and I started taking anticoagulants, but I worsened, especially in my breathing. The shortness of breath was so severe that I had to be taken to the hospital by ambulance. Only then did they perform a PCR test, which came back positive for Covid-19. (Berthier, 2022)

When I had flu-like symptoms, I took a Covid test, which came back negative. No one gave me any guidance about the symptoms or the need to repeat the test. On my own initiative, I took another test to retest, which came back positive for Covid-19. I was very worried because the lack of guidance could have worsened my health or caused me to transmit the virus to my family. (Louise, 2023)

The accounts from Berthier and Louise highlight a latency period between the onset of initial symptoms and the request for a Covid-19 test by healthcare professionals. This interval was largely due to the absence of adequate support, marked by a lack of qualified listening and accessible communication. As a consequence, there was a delay in defining the therapeutic approach and in the appropriate referral for treatment of the disease.

Regarding the right to access health, Article 3 of Law No. 10,436, of April 24, 2002, which recognizes Libras (Brazilian Sign Language) as a legal means of communication and expression, establishes the guarantee of adequate care and treatment for deaf people¹⁶. Complementarily, Decree No. 5,626, of December 22, 2005, regulates this law and, in its Chapter VII, Article 25, items IX and X, ensures that public health services, including the Unified Health System (SUS) and companies that are concessionaires of public health care services, must have professionals trained in the use of Libras or in its translation and interpretation. Furthermore, it provides for support for the training and continuing education of these professionals, with the aim of guaranteeing effective communication and humane care for the deaf population¹⁷.

It is important to highlight that the right to health is one of the fundamental rights guaranteed to people with disabilities, as provided for in Article 8 of the Statute of Persons with Disabilities¹⁸. This article establishes that it is the duty of the State, society and the family to guarantee, as a priority, the realization of rights related to life, health, education, accessibility, communication, dignity, among others, as advocated by the Federal Constitution¹⁹, the Convention on the Rights of Persons with Disabilities and its Optional Protocol, in addition to the current laws that ensure the personal, social and economic well-being of this group²⁰.

In addition to these points, other factors in the interviewees' trajectories that hindered access to healthcare were also listed:

I sought medical attention during the pandemic with flu-like symptoms, accompanied by my husband, who is hearing. However, he was not allowed into the consultation room. I informed the professionals that I am deaf and requested that they lower their masks so that I could lip-read and better understand facial expressions, but my request was refused. The consultation was quick, without detailed explanations, and the doctor communicated with me only through written Portuguese. (Hellen, 2022)

In Hellen's account, it is observed that she possibly did not feel comfortable attending the appointment alone, opting to be accompanied by her hearing husband, who could act as an informant with the doctor. However, the prohibition of a companion's presence during the consultation forced the patient to ask the

professional to lower their mask to allow for lip reading, a request that was refused. This situation highlights that, both for deaf people who use cochlear implants and for deaf people who speak Libras (Brazilian Sign Language), visual elements, such as facial expressions, lip reading, and other visual cues, are fundamental for comprehension during communicative interaction. Finally, communication between patient and professional was restricted to written Portuguese, which may limit the effectiveness of the appointment.

Every time I had Covid, the professionals communicated through writing. There was no illustrative or accessible material in Libras (Brazilian Sign Language) for information. (Jeanne, 2023)

The use of masks greatly interfered with lip reading and facial expressions. All healthcare professionals should know sign language. (Desloges, 2024)

The lack of bilingual support during the pandemic was total. When deaf leaders received information, we would do live streams to share it with other deaf people who can't read or have difficulty with Portuguese, or some would send me private messages asking for help with some content. (Gertrude, 2023)

Regarding healthcare services, in terms of accessibility, it was terrible because most professionals wore masks, and it was quite poor. I had to communicate through writing, or I needed to ask an interpreter to accompany and help me. (Annie, 2023)

The accounts of Jeanne, Desloges, Gertrude, and Annie highlight the absence of sign language interpreters in health services, as well as the lack of preparedness of health professionals in providing care in Libras (Brazilian Sign Language), factors that significantly compromise the quality of care provided to the Deaf population. Given this scenario, it is necessary to revisit the precepts of the 1988 Federal Constitution, which, in its article 23, item II, establishes as a common competence of the Union, the States, the Federal District, and the Municipalities to ensure the protection and guarantee of people with disabilities, including health care and public assistance¹⁹. Furthermore, article 196 reinforces that health is a right of all and a duty of the State, guaranteed through social and economic policies that promote the reduction of risks and ensure universal and equal access to health services¹⁹. These legal provisions reinforce the urgency of adopting measures that ensure the presence of bilingual professionals (Brazilian Sign Language/Portuguese) and TILSP (Translator and Interpreter of Brazilian Sign Language) in health services, in order to effectively guarantee the right to health of the deaf population, as determined by the Brazilian Constitution.

It is observed, therefore, from the analyzed reports, that significant gaps still persist in access to health services that consider the cultural and linguistic specificities of deaf people. The demands related to accessibility highlight the urgency of developing communicative skills in sign language among hearing health professionals, in order to promote effective and humanized communication in interpersonal relationships with deaf patients.

DISCUSSION

Narratives related to access to health services during the Covid-19 pandemic revealed that the educational, cultural, and linguistic specificities of the deaf population were not adequately considered, significantly compromising the quality of interaction between hearing professionals and deaf patients, even in the face of guarantees ensured by Brazilian law¹⁶⁻²⁰. The lack of linguistic accessibility in a health emergency context goes beyond a communicational difficulty, as it restricts access to fundamental information for prevention, symptom recognition, seeking care, and making decisions related to one's own health⁸. Thus, the barriers identified in the narratives exposed deaf people to conditions of greater vulnerability precisely during a period in which clear, understandable, and accessible information was indispensable for protecting health and life.

Reports revealed that, when seeking care, deaf people who use Libras (Brazilian Sign Language) already expected not to be received in their preferred language. The anticipation of potential communication difficulties led to a more stressful and insecure experience when seeking healthcare, as there was already a possibility of not being understood by professionals. This scenario was aggravated by the restrictions imposed during

the pandemic on the presence of companions during consultations. In various situations, a hearing companion could act as an informal mediator of communication, contributing to the understanding of information provided by professionals and to the expression of the needs of the person being cared for. The impossibility of having this support, in certain situations, removed an important possibility for communication mediation, adding to the uncertainties related to the symptoms and diagnosis of Covid-19.

Another recurring aspect in the narratives refers to the barriers arising from the use of face masks. The refusal of professionals to remove them, even momentarily and when this request was necessary for communication, hindered lip reading and the visualization of facial expressions, elements relevant for deaf people who use signing and/or oral communication, including those who use hearing aids and/or cochlear implants. Even when AEDs are used, visual cues can play an important role in understanding communication^{6,8}. Thus, a measure indispensable for containing the spread of the virus simultaneously produced additional barriers to communication for part of the deaf population, highlighting the need to reconcile individual protection measures with accessible communication strategies.

Difficulties were also observed in the predominant use of written Portuguese during consultations. This practice may be associated with the mistaken assumption that all deaf people have sufficient command of this modality of the majority language. However, the different educational paths and levels of proficiency in Portuguese make its use as the sole communicative resource inadequate⁷. Written communication, when used exclusively, does not ensure that clinical information is effectively understood, and may compromise the communication of symptoms, the understanding of instructions, adherence to preventive measures, and the monitoring of conduct indicated by professionals⁵.

This situation further highlights that deaf people do not constitute a homogeneous group, presenting different linguistic, educational, and cultural experiences²¹⁻²³. Therefore, it cannot be assumed that all use Libras (Brazilian Sign Language), master written Portuguese, or perform lip reading. Recognizing this diversity is fundamental so that health services do not adopt a single communication strategy as a universal response. On the contrary, guaranteeing linguistic equity requires offering resources compatible with the needs of each person served.

Communication barriers were also present in the circulation of information about Covid-19. Jeanne's account highlighted that much of the information on prevention and guidelines related to the disease, disseminated during the pandemic, did not include Libras (Brazilian Sign Language). This scenario was accompanied by the absence of a Libras window and adequate subtitles in official information broadcast on open television, as well as inaccuracies in automatic subtitles and delays in processing and generating these resources on digital platforms³⁻⁴. In a period marked by the constant updating of health recommendations, such limitations made it difficult to follow the guidelines and increased the exposure of Deaf people to incomplete or inaccessible information.

The extent of this gap can also be seen in the survey conducted by Galindo Neto *et al.*²⁴, who analyzed 402 videos available on *YouTube* with information about Covid-19 in Libras (Brazilian Sign Language) during 2020. Of these, 260 (64.7%) were published on channels by individuals and only 142 (35.3%) on institutional channels. These data reveal a significant participation of individual initiatives in the production and dissemination of information in Libras, while also highlighting the insufficiency of institutional action in offering accessible content. In a health emergency, guaranteeing the right to information cannot depend predominantly on the initiative of individuals or leaders of the community itself.

In this scenario, deaf researchers and leaders played a fundamental role in the production and dissemination of information on the prevention, diagnosis, and treatment of Covid-19 in Libras (Brazilian Sign Language), using their own channels and social networks. These initiatives contributed to expanding the circulation of understandable information and fostered forms of support and connection during a period marked by social isolation²⁴. However, the mobilization of the community itself should not replace the institutional responsibility to ensure accessible health information, since access to information and communication in Libras is a right guaranteed by Brazilian law¹⁶⁻²⁰.



Finally, the interviewees highlighted the need to expand training in Libras (Brazilian Sign Language) in health-related courses, not just in Speech Therapy. The inclusion of this curricular component can contribute to future professionals developing knowledge about the language, culture, and different forms of communication of deaf people, favoring care practices more suited to their needs^{5,25}. However, training in Libras must be linked to a broader understanding of linguistic rights, the existing plurality among deaf people²²⁻²³, and the institutional responsibility for offering accessible services. Ensuring that a deaf person can be understood and understand the information necessary for their health care is not an additional benefit, but an indispensable condition for the realization of the right to health, information, and the protection of their own life.

CONCLUSIONS

The analysis of the (auto)biographical narratives of the seven deaf participants revealed the persistence of linguistic and communicational barriers in experiences related to health, education, and social interaction during the Covid-19 pandemic. Although the pandemic period created exceptional circumstances, the accounts demonstrated that a large part of the difficulties faced were not circumstantial, but were related to structural barriers historically present in the relationships established between deaf people and different services, institutions, and social spaces. The pandemic, therefore, did not produce these inequalities, but made them more visible and, in certain situations, intensified their effects.

The findings demonstrated that the restriction or inadequacy of communication possibilities in Libras (Brazilian Sign Language) directly impacted the understanding of information, participation in everyday situations, decision-making, and the autonomy of deaf people. In the field of health, these barriers took on particular gravity, since limited access to linguistically accessible information and services can compromise the understanding of guidelines, the communication of symptoms and needs, and the very possibility of participating in decisions related to care. In a context of a health emergency, in which accurate and timely information was fundamental for prevention and health protection, the lack of linguistic accessibility revealed an inequality that cannot be understood as secondary or merely communicational.

The narratives also highlighted the centrality of Libras (Brazilian Sign Language) for social participation, access to information, expression, and the exercise of autonomy. Its presence should not be understood as a complementary resource or a simple adaptation of existing services, but as a necessary linguistic condition for the realization of rights. Guaranteeing communication in Libras means enabling deaf people to understand information, express their needs, participate in decisions that concern them, and establish social relationships under conditions of equity.

The results indicate that overcoming linguistic and communication barriers requires permanent, planned, and coordinated actions among different social sectors, especially health and education. Training professionals to work in bilingual contexts, improving service quality, offering translation and interpretation between Libras (Brazilian Sign Language) and Portuguese, and systematically providing information in Libras are essential measures to ensure effective conditions for participation, autonomy, and the exercise of citizenship. These actions should not be understood as extraordinary measures, but as part of institutional responsibilities related to guaranteeing rights.

In this sense, the responsibility for linguistic accessibility cannot be transferred to deaf people themselves, their families, or support networks. The mobilization of leaders, researchers, and members of the deaf community to produce and disseminate information in Libras (Brazilian Sign Language) during the pandemic demonstrated the organizational capacity and leadership of this community, but also highlighted gaps in institutional action. The initiative of the community itself was fundamental in expanding the circulation of accessible information, but it should not replace the responsibility of the State and institutions in guaranteeing communication, information, and service under conditions of equity.

The findings further reinforce the idea that deaf people do not constitute a homogeneous group and that their linguistic needs cannot be reduced to a single form of communication. Policies, services, and institutional

practices need to recognize the diversity of existing linguistic, educational, and cultural experiences, avoiding generalizing assumptions about deaf people and in defining actions that concern them.

In summary, this study contributes to making visible, through the (auto)biographical narratives themselves, the linguistic and communicational barriers that deaf people experienced during the pandemic and that remain challenges to the realization of their rights. The findings show that linguistic accessibility is not a concession, benefit, or exceptional measure, but an indispensable condition for the exercise of citizenship, for the guarantee of rights, and for the recognition of the dignity and lives of deaf people.

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APPENDIX 1 - Conversation Outline

1. Is your deafness congenital or acquired? If acquired, at what age and what is the cause?
2. Are your parents deaf or hearing?
3. What was your family's decision after the diagnosis of deafness?
 - 3.1 Educational Approach:
 - 3.2 Use of hearing aids / IC surgery.
4. Do you know sign language? If so, how did you learn it?
5. Do you belong to any community or association for the deaf or hard of hearing?
6. What is your educational level?
7. What most marked your life during the *lockdown periods* during the pandemic? Coronavirus?
8. Has being isolated at home changed your relationship with your family, your friends, and your work?
9. Have you had Covid-19 or suspected you may have contracted the virus? What was that experience like for you?
10. Have you experienced depression or anxiety and needed medication or professional, religious, or other types of help?
11. During the pandemic, did you have any other illnesses or health problems? What were they?
12. At school, health centers, and public services, did you have difficulty expressing your doubts, suffering, or health problems? In other words, did you find an accessible and welcoming environment?
13. During the pandemic, did you experience any type of violence, harassment, or mistreatment? If so, in what situations did you feel threatened?
14. If you are a student, do you study at a private or public school or higher education institution? What grade level are you enrolled in?
15. Can you tell me about your experience with remote teaching?
16. During remote learning, did you fail any subjects? Which ones?
17. Do you think your school or higher education institution was accessible and welcoming during the time you were taking your courses? Can you talk about that? What recommendations would you give to school or higher education institution principals in the case of Deaf students in remote learning?
18. Did you consider dropping out of school during remote learning? If so, why?
19. Did you drop out of school or higher education institution during remote learning?
20. How were the assessments for the subjects conducted and graded in remote learning? What were your grades like?
21. Tell us about your experience with remote teaching during the pandemic (access to and autonomy in using digital platforms / presence of a sign language interpreter / availability of adapted activities).



22. What grade would you give your school or higher education institution in relation to your needs as a student?
23. Was there a situation at school that really affected you? If so, could you talk about it?
24. In remote teaching, on digital platforms, could you see the teachers and students, or did you only have access to the TILS (Translator, Interpreter, Sign Language) image?
25. If you only had the image of TILS (Translator, Interpreter, Sign Language), how would you rate your learning experience compared to your classmates?
26. Which subject did you enjoy the most, and how did the teacher teach it?
27. And what's the worst subject for you? Why?
28. If you are no longer a student, what recommendations would you give to the administration of an inclusive school or higher education institution to ensure that deaf students remain enrolled on equal terms with other students?
29. Do you have any news about how remote learning went in bilingual schools or classes?
30. If you study in a bilingual class or school: how was the period of remote learning? And how did you feel when classes were able to resume?
31. How was the healthcare experience when you were tested for Covid-19? If you tested positive for Covid-19, what was the journey from diagnosis to recovery like?
32. What message would you like other deaf people, teachers, and principals to read or learn from your experience during the pandemic?



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