



## DEAFNESS AND HEALTH CARE: CHALLENGES TO THE IMPLEMENTATION OF THE CARE NETWORK FOR THE DISABLED

*Atenção à saúde e surdez: desafios para implantação da rede de cuidados à pessoa com deficiência*

*Atención a la salud y la sordera: desafíos de la implantación de la red de cuidados a la persona con discapacidad*

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### ABSTRACT

**Objective:** To assess the health care provided to deaf people who use the Brazilian sign language (Libras), from their own perspective, aiming to reflect on the inclusion of actions into the Care Network for the Disabled. **Methods:** Study with a qualitative approach, conducted in 2010, with participation of fifteen deaf adults who use Libras. The techniques employed were focus group and open interview with simultaneous translation from the Brazilian Sign Language into Portuguese. **Results:** This study evidenced three thematic categories: barriers within the health services; attitudes to minimize communication barriers; and suggestions for improving health care delivery. This information may interfere with comprehensive and humanized health care. As a result of the difficulties, deaf people and health professionals resort to different strategies to enable care. **Conclusion:** The study made it possible to know the peculiarities of health care for deaf people, users of sign language, evidencing challenges during care delivery due to a restricted communication, so that sign language can be one of the ways for effective communication with these users in health services.

**Descriptors:** Deafness; Disabled Persons; Sign Language; Communication Barriers; Health Care; Public Health.

### RESUMO

**Objetivo:** Conhecer a assistência à saúde prestada às pessoas surdas, usuárias da Língua Brasileira de Sinais (Libras), a partir da sua perspectiva, com vistas a refletir sobre a inclusão de ações na Rede de Cuidados à Pessoa com Deficiência. **Métodos:** Estudo de abordagem qualitativa, realizado em 2010, com participação de 15 surdos adultos, usuários da Libras. Foram aplicadas as técnicas de grupo focal e entrevista aberta, com tradução simultânea entre a Língua Brasileira de Sinais e o português. As informações coletadas foram submetidas à análise temática. **Resultados:** O estudo evidenciou três categorias temáticas: barreiras nos serviços de saúde; atitudes para minimizar as barreiras de comunicação; e, sugestões para melhoria da assistência nos serviços de saúde. Essas informações podem interferir na assistência integral e humanizada à saúde. Em razão das dificuldades, surdos e profissionais de saúde recorrem a distintas estratégias para viabilizar o atendimento. **Conclusão:** O estudo possibilitou conhecer as peculiaridades da assistência à saúde às pessoas surdas, usuárias da língua de sinais, percebendo-se desafios durante o atendimento em virtude de uma comunicação restrita, de forma que a língua de sinais possa ser um dos caminhos para uma efetiva comunicação com esses usuários nos serviços de saúde.

**Descritores:** Surdez; Pessoas com Deficiência; Linguagem de Sinais; Barreiras de Comunicação; Atenção à Saúde; Saúde Pública.



## RESUMEN

**Objetivo:** Conocer la asistencia de salud de personas sordas usuarias de la Lengua Brasileña de Señales (Libras) desde su perspectiva para reflexionar sobre la inclusión de las acciones de la Red de Cuidados a la persona con discapacidad. **Métodos:** Estudio de abordaje cualitativo realizado en 2010 con 15 sordos adultos y usuarios de Libras. Fueron aplicadas las técnicas de grupo focal y entrevista abierta con la traducción simultánea de la Lengua Brasileña de Señales para el portugués. Las informaciones recogidas fueron sometidas al análisis temático. **Resultados:** El estudio evidenció tres categorías temáticas: barreras de los servicios de salud; actitudes para disminuir las barreras de comunicación; y sugerencias para la mejoría de la asistencia de los servicios de salud. Esas informaciones pueden influir en la asistencia integral y humanizada de la salud. A causa de las dificultades los sordos y los profesionales sanitarios recurren a distintas estrategias para hacer la atención viable. **Conclusión:** El estudio ha posibilitado el conocimiento de las peculiaridades de la asistencia a la salud de personas sordas, usuarias de la lengua de señales percibiéndose los desafíos durante la atención debido una comunicación restricta de manera que la lengua de señales puede ser uno de los caminos para una comunicación efectiva con los usuarios de los servicios de salud.

**Descriptor:** Sordera; Personas con Discapacidad; Lenguaje de Signos; Barreras de Comunicación; Atención a la Salud; Salud Pública.

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## INTRODUCTION

The Health Care Network represents a way to fully organize health actions and services of different technological densities, aiming at improvement in access, comprehensive care, effectiveness of actions and economic efficiency<sup>(1)</sup>.

The Network of Care for Disabled Persons (*Rede de Cuidados à Pessoa com Deficiência - RCPD*), established by Ordinance no. 793 of April 24, 2012<sup>(2)</sup>, is a priority network to be implemented in the different health regions of the country. Humanized, comprehensive health care, which is focused on people's needs and, therefore, diversified in its strategies, emerges as a guideline for the functioning of this network<sup>(2)</sup>. In agreement with the logic established by this ordinance, offering services based on the needs of the population served and the health regions is a fundamental attribute for the functioning of the care network<sup>(1)</sup>. Identifying persons with disabilities and their needs is imperative to arrange a work in the logic of care networks.

The statistical census of the Brazilian population, carried out by the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística - IBGE*), provides indications regarding the number of disabled persons. The 2010 Census estimated 45 million people with disabilities, including 9 million with a hearing impairment and 2 million with a severe hearing problem<sup>(3)</sup>. In this universe, it is assumed the existence of deaf sign language users, which use the Brazilian Sign Language (Libras) as a means of expressing ideas, feelings and values, and interpret the world mainly through the visual means of communication. The linguistic condition of deaf people poses daily challenges to their access to health services, given that, while they communicate in a visual-motor language, the services are offered, almost exclusively, in an auditory-oral language. The cultural linguistic difference between Portuguese and Libras demarcates an important frontier in the health care for deaf people, which needs to be investigated, since it can give rise to barriers in the provision of health care. According to the Social Model of Disability, the conditions of the environment and the barriers to participation are also causative factors in disabilities and impairments. In this model, despite being regarded as a consequence of the disabilities, it is no longer at the center of the discussion<sup>(4)</sup>. The new model proposed for organization of health actions and services aimed at persons with disabilities should consider not only issues involving functional limitations, but also the environmental conditions and barriers, or hindrances.

The Network of Care for Disabled Persons is a model of attention directed at the population that expresses some organic or functional impairment of physical, sensorial and intellectual nature. Such classification includes people with motor, visual, hearing, intellectual impairments, ostomies, and with multiple disabilities.

The ordinance that enacted this network has its origin in the National Plan for the Rights of Persons with Disabilities (National Plan Living Without Limits)<sup>(5)</sup>, which defines inclusive actions related to education, work, accessibility and health. In Health, the implementation of the care network aims at qualifying the attention to the disabled person through the organization of a network of comprehensive care within the scope of the Brazilian Unified Health System (SUS) (2). Effectively, the network will function through the interaction of its constituent elements: defined population and health region, operational structure (composed of care settings with a variety of technological densities, and that offers health services) and logical system, foundation of its operation<sup>(1,2)</sup>.

The Network of Care for Disabled Persons should have an operational structure<sup>(2)</sup> organized with the support of three specific components, which should be articulated to provide health care: Basic Care, comprised by the Basic Health Units, covering the services of the Family Health Support Center (NASF) and the Dental Care; Specialized Care in Rehabilitation, which encompasses, as health facilities, the ones qualified in only one type of Rehabilitation Service, the Specialized Centers in Rehabilitation (CERs) and the Dental Specialties Centers (CEOs); and Hospital, Urgent and Emergency Care. The three components express strategic care settings for conformation of this network, and should be complemented by additional ones depending on the users' health needs.

Four phases were defined for implementation of the Network of Care for Disabled Persons<sup>(2)</sup>: the first one relates to the diagnosis and regional design of the network, which includes the drafting and agreement of the network design and the regional and municipal action plans; the second phase concerns the adherence to the network, with the establishment of the State Coordination Group and the homologation of the initial region for implementation of the Care Network; the third one addresses the contractualisation of the care facilities by the responsible entity, which will occur after getting the municipal design ready, and in compliance with the joint responsibility for the regional network; whereas the fourth phase deals with the implementation and monitoring of the care actions defined in the Network of Care for Disabled Persons by the State Coordination Group.

In 2012, the State of Ceará initiated the debate for organization of the Network of Care for Disabled Persons. During that period, the State Coordination Group managed, monitored and advised the elaboration of 16 regional plans that comprised the 2013-2016 State Plan for Structuring the Network of Care for Disabled Persons<sup>(6)</sup>. In the health regions, in general, the municipal and state managers and technical advisors discussed, in the Regional Interagency Committee (*Comissão Intergestores Regional - CIR*), the regional design of the networks and agreed the care settings for provision of the services. After being discussed, the plans were forwarded to the State Coordination Group for analysis and, when granted approval, received homologation in the Bipartite Interagency Committee (*Comissão Intergestores Bipartite - CIB*) and were sent to the Ministry of Health for evaluation of costs and possible financing.

In the period between 2013 and 2016, the implementation of 16 thematic networks was conceived in the State Plan, with 39 Specialized Centers in Rehabilitation (named by the Portuguese acronym CER). Each year, four networks were stipulated for implantation<sup>(6)</sup>. After intense drawing of the network design and agreement of care settings among the managers, three CERs, of the 39 conceived in the plan, are under construction in Ceará (in Tauá, Juazeiro do Norte and Eusébio). Three other equipments were qualified to provide care in two types of deficiencies, and privilege the specialized care for hearing impairment, and these are one CER II in Sobral and two CER II in Fortaleza.

In the elaboration of the Network of Care for Disabled Persons, it was observed a collective effort on the part of the managers and technicians of the 22 health regions, in order to draw and elaborate a proposal for structuring the care network in the state focused on the construction of Rehabilitation Centers, which, in practice, has not been accomplished and needs to be rethought.

The Brazilian Law on the Inclusion of Persons with Disabilities, no. 13,146/2015<sup>(7)</sup>, ensures the participation of persons with disabilities in the elaboration of policies aimed at them. In this sense, studies that focus on the disabled users's perspective on their own care process should be encouraged.

The study is relevant, because it problematizes events experienced by the deaf themselves in the health services, making it possible that information from the research give rise to discussions on the specificities of this service, and serve as a means to rethink the practices involved in health care and to guide the planning of actions in the Network of Care for Disabled Persons, with a view to improving the provision of services to these users and supporting the organization and operationalization of the care network.

Therefore, the objective is to assess the health care provided to deaf people who use the Brazilian Sign Language (Libras), from their own perspective, aiming to reflect on the inclusion of actions into the Network of Care for Disabled Persons.

## METHODS

This qualitative study<sup>(8,9)</sup> was carried out in the city of Fortaleza, located in the Northeast of Brazil, in order to know the experiences of deaf people in the health services, and, based on that, reflect on the attention to these people in the context of the care networks.

The health sector traditionally recognizes the opinion of experts and professionals as relevant for the planning, organization and evaluation of services. The studies of qualitative approach differ from tradition, when considering the existence of multiple points of view to understand the phenomenon under study<sup>(8)</sup>. In this sense, the experiences of the users - and, in this context, the deaf users - are of great importance, as well as that of other agents that compose the service, for the understanding of the phenomenon under examination.

The research, held in 2010, took place at a public institution linked to the State Education Secretariat, located in the city of Fortaleza, Ceará. The purpose of the institution was to provide the deaf and their family members with services, such as: promoting Libras courses and other training courses, disseminating programs and events that address deafness-related issues; providing family counseling, and often providing specialized services directed at deaf persons' learning. In this space, the deaf gathered in order to discuss and exchange experiences on the various subjects related to the daily life of the deaf community and, therefore, it represented a powerful space for debating and understanding the experiences of deaf people when they seek the health services.

In fact, the informants were chosen because of their relevance to the research question<sup>(9)</sup>. The inclusion criteria were: being deaf, over the age of eighteen, and participating in the activities of the institution. Fifteen deaf people participated, being nine instructors of Libras and six pre-college students of both sexes, with age ranging from 18 to 47 years. Concerning the instructors'schooling, the lowest level reported was incomplete higher education, with some reporting one undergraduate

degree or attending a second undergraduate course or a graduate course. All of them reported using Libras in their day-to-day communication.

The first contact with the group of instructors occurred at the meeting they held weekly. Mediated by an interpreter, a presentation was made by one of the researchers, who explained the objectives and methodology of the research. In the dialogue with the group, it was suggested by the deaf themselves that there should also be a discussion with pre-college students. After finishing the presentation, the date for the first focus group was scheduled, to be held at the very institution, as suggested by the deaf themselves.

As the techniques for production of empirical material, the study resorted to focus group and open interview<sup>(8)</sup>, with simultaneous translation-interpretation of Libras into Portuguese, and vice versa, by interpreters. The focus group took place in four sessions and aimed at understanding the participants' experiences in group interaction, the access to opinions, their confrontation and agreement. Two sessions were carried out with teachers who conduct Libras courses at the institution hosting the research, and two others with pre-university students of the institution. The script adopted by the focus group included the following guiding questions: What is it like for you to be deaf? What is the day-to-day life of a deaf person like? The questions that emerged from the guiding questions were: How does your access to health, education, financial services and others occur? What suggestions would you make in order to improve communication in the health service, financial service, in general services?

The individual interview was carried out in complementation to the focus group, for better understanding of the investigated object, and aimed at deepening the topics pointed out in the groups. At that occasion, there was the participation of five deaf people, identified as good key informants, those with knowledge of the subject matter and facility for expressing it<sup>(10)</sup>.

The empirical materials produced were recorded in video and audio, and the reports were transcribed, subjected to an initial reading for impregnation of the meaning, and analyzed according to the thematic analysis<sup>(11)</sup>. In this phase, central themes were identified, the analytical and empirical categories that composed the network of meanings of the research. The following categories were then constituted: a) Barriers within the health services; b) Attitudes to minimize communication barriers; and c) Suggestions for improving care delivery in the health services.

The research was approved by the Research Ethics Committee of the Federal University of Ceará - COMEPE according to Opinion 324/09, in line with the norms of Resolution 196/96 of the National Health Council, which regulates ethics in research involving human beings, and is also in agreement with Resolution 466/12<sup>(12,13)</sup>.

The initial letter of the word *deaf* (D) followed by the number of events of the interviews (D1, D2, D3, successively) was used to identify the interviewees' reports and guarantee their anonymity.

## RESULTS AND DISCUSSION

In the analysis of the information produced in the research, meaning nuclei were identified and classified as categories, constituting the central themes that composed the network of meanings of the study. In this topic, the three thematic categories that emerged from the study will be expressed and discussed: Barriers within the health services; Attitudes to minimize communication barriers; and Suggestions for improving care delivery in the health services.

### Barriers within the health services

This category addresses the barriers encountered by deaf persons within the health services, highlighting the barriers to communication between hearing health professionals and the deaf persons seeking care.

The practice of care, because it involves relational aspects, requires care practices that consider the interpersonal communication skills. Difficulties in communication and information between caregivers and users who seek health services can compromise care, in result of the difficulty in mutual understanding, thus configuring a failure in humanized and inclusive care. The obstacles experienced become even more worrying when an inadequate communication gets to compromise the diagnosis of health problems and the patient's treatment<sup>(14-16)</sup>.

*"[...] sometimes I felt a pain, some problem, or I was vomiting, then I decided to see a doctor [...] I explained that I was evacuating too much, and he wanted to put me on a drip. I would be there for about three hours and the doctor would not even attend to me properly. I would go home and the bellyache would persist again, feeling sick. I went to the doctor again and it was all the same, he only put me on IV, I went home. [...]. The doctor could not understand that I was evacuating, that I had a bellyache and that I was sick; it was very difficult to communicate, I needed an interpreter. Then my mother went along and explained it, it was all done, they gave me the medicine, I took it and I got well, but on my own, it always went on about a drip" (D8).*

*"[...] I couldn't explain what I was feeling, nor could I understand what the dentist was telling me that had to be done. Everyone staring at me, I died of shame, I didn't know what to do. It was such a simple thing and it was only about taking and cleaning the tooth, then I went on and wrote it down. He couldn't believe me, I was scared to death. [...] The interpreter went there and explained to the dentist what the visit was about, that it was only about having my teeth filled and cleaned, but the dentist thought it was about having it pulled... we have a lot of trouble" (D2).*

Only through effective communication will the professional be able to understand what the patient expresses and thus help him to recognize and confront the process of illness and health<sup>(17,18)</sup>. At the end of the consultation, however, some patients do not understand their problem, nor the reasons that led to the prescription of the medication administered<sup>(19)</sup>.

On a day-to-day basis, reality confirms the shortage of health professionals who communicate properly with deaf people. Only a few know the sign language and the peculiarities of the deaf culture, and an even smaller number communicates through that language.

Foreign research has identified insufficient training of a large number of physicians to attend to deaf people who communicate primarily through the sign language, and the lack of knowledge, on the part of the professionals, regarding deafness and the deaf people's distinct ways of communicating<sup>(15)</sup>. The occurrence of these facts is related to the gap in the training of medical students on the skills and abilities that facilitate the communication with the deaf patient, or those with hearing loss<sup>(20)</sup>. Likewise, it occurs with other healthcare professionals, and this fact is pointed out as a reason that causes an important hindrance in caring for these people<sup>(17,21)</sup>.

Including in the undergraduate courses information regarding hearing loss, physician-patient communication and techniques to improve the ability to listen to and learn the history of these patients becomes fundamental in the Medicine courses<sup>(20)</sup> and in the other undergraduate healthcare programs. In the same way, the different conceptions of deafness and deaf people must be addressed, including their physiological, symbolic and cultural dimensions<sup>(22)</sup>. Training in cultural skills for health professionals can also contribute to favor the access of deaf persons to the services<sup>(23)</sup>.

Based on the clinical-hegemonic-pathological design of the disability, the academic training disregards the social and cultural fabric of deafness<sup>(24)</sup>. Thus, despite the existence of efforts for the accomplishment of care, there is evidence of the professional's unpreparedness and mutual discomfort in attending to the deaf, compromising the care for them, as the deaf persons are not fully understood in their needs.

*"[...] it looks like the practitioner got nervous. How was he going to try to communicate with the deaf there, at that moment? I wondered what that doctor's reaction would be. Let's write it down, we wrote it, and the doctor got all ashamed and showed the writing and I understood 'body, body, are you in pain', then he wrote and I was weighing what would be the word he was going to put. Then I realized that the doctor was sweating, because he was not being able to communicate, and it was the most difficult thing of my life. When he wrote a word, I didn't understand, that doctor should really have at least the basics, to be able to have basic communication" (D7).*

A variety of feelings, among which are anxiety, fear, insecurity and impatience, occur during the consultation and, sometimes, they manifest themselves as a result of the professionals' unpreparedness to deal with this clientele<sup>(17,25)</sup>. Moreover, the further away the health professionals in the universe of their users, that is, the less they really know about them, the greater the discomfort when dealing with these persons. Concerning their peculiarities transposed to the sensorial impairment, an approach to this other individual arising from other dimensions - cultural, symbolic, social - that are important for the care, is rendered impossible.

In Brazil, with a view to overcoming the attitudinal, communication and information barriers, as well as to enabling care delivery to the deaf in the health services, laws and decrees have been enacted in this area in the past years, which has represented for the deaf community an important advance in their social inclusion. By providing that Libras must be a compulsory curricular discipline in teacher training courses for professorship, in the Speech Therapy course, and in other courses as an optional discipline, Decree 5,626/2005, which regulates the Brazilian Sign Language as a code for communication and expression of the deaf community, tends to induce the training of professionals to attend to this contingent<sup>(26)</sup>. The decret also encourages the qualification and training of professionals working within the Unified Health System (SUS) network on the use of Libras and its translation and interpretation.

Ten years after the enactment of the mentioned government regulation, in practice, one can observe the inclusion of the discipline Libras into the curriculum of undergraduate courses, and an increase in the offer of Libras courses in the extension and training modalities, conducted by both private companies and the public service, thus contributing to training, or at least to sensitizing the health professionals, and to the qualification of professional interpreters.

Although the deaf recognize the increase in the number of qualified medical sign language interpreters, the absence of an interpreter at the healthcare settings constitutes an obstacle to care, which violates the constitutional right to health. It is the responsibility of the State, according to the Citizen Constitution, to protect the health of all citizens, enabling, among other actions, fair and equal access to the set of actions and services offered by the Unified Health System (SUS):

*"[...] It used to be much worse before. Today it has improved, not much, let's say by forty percent. [...] In the past, it only worked with the family by our side. We had no interpreter, but rather a lot of mimes. But not today. The number of interpreters has increased, so we go to the doctor [...] we have an interpreter to go along, it has improved a lot, the problem is that we have to pay for that [...] but, even so, the accessibility for us is far from the needed [...] There is a lack of government's incentive to pay for the interpreters." (D1).*

### Attitudes to minimize communication barriers

Despite the improvements achieved through government regulations, the deaf are still responsible for solving or minimizing communication and information barriers in the clinical encounter with hearing professionals. Because of the reduced possibility of dialogue, most of the times, they seek the services accompanied by a family member or friend, requiring a third person to mediate the consultation<sup>(21)</sup>. They complain, however, that in the company of that person, important data are transmitted to them in a partial way, rendering them deprived of information about their health status/illness, which, somehow, affects their autonomy.

*"[...] My mother and I went to see the gynecologist, and I was asked something and I told my mother that I understood more or less. She said that everything was normal, all normal, but really, I couldn't understand what I was feeling [...] to the hospital, I don't have the courage to go by myself" (D11).*

*"[...] I understand when my mother-in-law talks to me, but not when my mother talks. My mother speaks more to the doctor than to me. I went there several times with her, and I couldn't understand" (D7).*

Although the hearing companion helps in the care, in some cases, they may represent a problem: when they prevent the deaf person from leading their own care and from making the decisions pertinent to their health, manifesting, during the clinical encounter, an passive attitude<sup>(27-29)</sup>. Because they do not understand their role as mediator in the communication between the deaf and the health professional, the family member, despite trying to help, invades the consultation space, interfering in the relationship between the two. In the exercise of their autonomy and in search of the full understanding of the consultation, those who can afford it resort to the private interpretation service, an option for only a few, though. The deaf participants of the present study, given that they use Libras as first language, point out the use of this communication modality during the consultation as primordial for them to feel understood. Such reality has also been observed in other studies, whose research was performed with deaf people who communicate through the sign language<sup>(29,30)</sup>. Nevertheless, due to the hearing professional's unpreparedness to deal with this clientele, or even the absence of interpreters within the services, the deaf and the practitioners make use of several communicative resources, including writing, in order to enable the care. The deaf recognize, however, difficulties in understanding written Portuguese:

*"[...] I fell down, and I want to explain what happened, how will this service help me out if I can't even understand it? That's the difficulty. Sometimes I use mimes to communicate myself" (D7).*

*"[...] I decided to see the doctor all alone, I showed him where I was feeling pain [...] I raised my shirt and showed him saying 'see, this is where it hurts', then he went and squeezed there, looked, then asked 'what do you eat?' Then he gave a lecture, well, really based on mimics, and wrote. But when he writes we don't understand. There are too many letters and I couldn't understand [...] So what we do is take the phone number, make a call, and ask him to pass the information to some family member or interpreter, and they pass it on for us. Let's say, the medical prescription. I give him the number, or someone calls me, then he explains about the time and the medicine that must be taken, then these are the annoying things, understand? About us being still dependent on that" (D1).*

Mimics and gestures are valuable nonverbal signals, being routinely used in the face of the communication difficulties that occur during the consultation. Short messages are rendered understandable by making use of these resources. Likewise, it is possible to recognize signs that are regarded as universal, such as an the expression of pain, but they require extraordinary efforts for adequate understanding and a longer consultation time<sup>(27)</sup>. In a more complex communication, such as when one wants to know more about the patient's history, these strategies are less effective, increasing the odds of errors in the interpretation of the message<sup>(18,25)</sup>.

In effect, third-party assistance (family member or interpreter) by telephone is a possible strategy, in view of extreme situations (an explanation of prescription drugs, in an attempt to minimize potential errors that compromise their health), although they interfere with the deaf person's autonomy. The use of technical terms and illegible writing make it even more difficult to recognize the message<sup>(27)</sup>. In case the professional uses the writing, it is convenient to make use of readable letter and short sentences, simplify terms and keep calm during the interaction<sup>(31,32)</sup>. The writing resource, despite being valued by hearing professionals<sup>(32)</sup>, can represent an impediment when used as a unique resource, especially for deaf people who have little understanding of written Portuguese. The use of writing was pointed out as one of the communication strategies that hinders the access of deaf persons to healthcare, but this is one of the resources most frequently used by professionals in interaction with the deaf<sup>(21,30)</sup>. For many deaf persons, written Portuguese is the second language, and there may be difficulties in mastering it<sup>(33)</sup>, as they also face difficulties in accessing the educational system.

Understanding that the deaf communicate in many ways means overcoming the homogeneous view of the deaf universe. There are deaf people who communicate through sign language; others make use of speech. Some use lip reading; others communicate through writing, others exclusively through gestures, and there are also those who make use of more than one modality of communication. In the study under report, all deaf persons communicated through sign language, but some performed lip reading, others used the modality of written Portuguese and some oralized a few words. Several strategies can be used in the appointment between the deaf and the health professionals. It is up to them to choose the communication

strategies that enable better understanding and facilitate access to care<sup>(17)</sup>. Once the professionals are trained in these skills, it will facilitate the interaction, reducing potential barriers. Knowing the strategies for communicating with deaf people, as well as the limitations to their use, helps to guide health professionals in dealing with them and, similarly, it also helps the manager in organizing the services based on the needs of those users.

Simple strategies, such as a visual panel in the healthcare setting for delivery of queue ticket numbers, and the communication between the reception room and the professionals, to notify them that the deaf person is in the waiting room, are of great value to enable access to services<sup>(31)</sup>. The following lines present the suggestions related to the care for deaf persons, which can be adopted at the care settings of the Network of Care for Disabled Persons.

### **Suggestions for improving care delivery in the health services.**

The deaf participants of the present study do not face the difficulties in health care with resignation. Instead, they make proposals and assign to the Government the role of encouraging and facilitating accessibility. One of the propositions is the use of sign language in the care settings of the network, either through the insertion of sign language interpreters or through the use of the sign language by trained professionals. They suggest that the Government invest in the training of health professionals in order to qualify them to apply this modality of communication. They point out, however, that the learning of Libras by hearing individuals will only occur, in fact, if there is permanent contact with the language. After being trained, many of them forget the signs. It was therefore recommended that the deaf, or the sign language interpreter, be included into the health services, so that a continuous interaction occurs, favouring an effective communication.

*“At [...] [a healthcare service], its employees have already come to take the course, but then we go there to be attended to and they have forgotten it, they don't even know how to talk to us, they can not interpret us, so this is the biggest difficulty. [...] There should be an interpreter in there, you see? Or else any deaf person should be there teaching the employees within the service, work directly in there, to be teaching the employees that have already taken the course, to be there at all times and interact with them” (D2).*

As for the professional work of the sign language interpreter in the health services, the deaf recognize and value their importance to mediate communication, proposing a way to organize their availability. Under the phone call regime, interpreters funded by the Government would be put into action to perform the interpretation, in case the health service did not have the professional. In 2014, the municipalities of Juazeiro do Norte and Fortaleza started to have Libras Interpretation Centers to serve the deaf. Likewise, in 2016, the Special Coordination of Public Policies for the Elderly and Persons with Disabilities, a state agency, also inaugurated a center. According to the Public Ministry of the State of Ceará, in 2016, the two municipalities expressed difficulties in providing the necessary assistance to the deaf person due to the small number of interpreters in employment<sup>(34,35)</sup>. A similar initiative was carried out in another Brazilian state, expressing itself as a recent fact in the history of social inclusion of the deaf person<sup>(21)</sup>.

Although interpreters are required in the health services, some deaf persons are not totally satisfied with the presence of this professional during the consultation addressing private issues, which proves an important point to be investigated:

*“I dream of the government paying an interpreter to be the whole time in a hospital, or somewhere else. Because sometimes we can't afford it. Let's suppose an association with three available interpreters paid by the government, and whenever any deaf person would need them, in case there was no interpreter at the healthcare setting, we could call and ask the interpreter to come at that moment, so the problem would be solved” (D2).*

*“[...] there are some private topics that unfortunately you get ashamed of bringing an interpreter along. So, if it's a very private thing of yours, you can ask your family to come with you, to write, but if it's just something, you can go with the interpreter” (D1).*

Some deaf people show discomfort in sharing some issues in the presence of the interpreter. Thus, for more reserved subjects, they prefer to be seen only by the medical practitioner who uses the sign language<sup>(25, 31,33)</sup>.

In Brazil, studies on interpretation in the medical context are virtually non-existent, and medical interpretation has not yet become an institutionalized occupation. Despite the existence of a growing demand for interpreters to work within the health service, there are no specific training courses to qualify professionals in the area<sup>(36)</sup>.

The policies on language and access promoted in Brazil in recent years reveal a perspective for sign language translation and interpretation within the health services. In this sense, the insertion of the interpreter needs to be discussed, since the skills and abilities necessary to act in the health services involve, in addition to the technical rigor for translation and interpretation of Libras into Portuguese language and vice versa, ethical issues related to secrecy and impartiality of the information, as well as the knowledge required in the area of health, for understanding and interpretation of the message in that context. Therefore, they must know, besides technical terms specific to the area, how to behave in this space, and the ethical issues related to health and illness that are required in the situation.

The importance of developing research in the area and creating curricula intended for the training of professional interpreters is highlighted, in order to structure this scope of practice and to train qualified interpreters for health care<sup>(36)</sup>. It is hoped that the courses offered for the training of translator interpreter of the Brazilian Sign Language will develop in these professionals the skills and abilities necessary to work in the health services, as well as an ethical attitude and professional responsibility, primordial precepts for their performance, as advocates the law regulating the profession<sup>(37)</sup>.

For the deaf to interact within their universe, a paradigm shift is required, which becomes effective through the respect to the differences<sup>(33)</sup>. The implementation of a care network based on the principles of comprehensive and humanized care can not become effective if there is no listening, bonding and dialogue among those who seek care and the care providers. The sign language, in the perspective of these deaf people, is the mechanism that enables this exchange and the success of their demands. In this way, its use should be encouraged in the settings of the care network, for access to health actions.

Primary Health Care (PHC), as the level of attention closest to users, plays an important role in the access to services and in the capacity to solve health problems. There is evidence, however, that the primary level is not organized to meet their needs, as the study points out that deaf people make more use of hospitals and services far from their domicile<sup>(38)</sup>.

The PHC, as one of the components of the Network of Care for Disabled Persons, should be organized to guarantee the care for deaf people in basic health units. Family Health teams, backed by professionals of the Family Health Support Center (NASF), can assess the number of deaf persons and their health needs, know the risks and vulnerabilities to which they are exposed, and enable the continuity of care in the network.

According to the ordinance regulating the Network of Care for Disabled Persons<sup>(1)</sup>, it is also possible to carry out home-based care, encourage inclusion and quality of life through community resources, and develop care lines that are able to guide the health care for deaf people. The Specialized Center in Rehabilitation (CER), despite being recognized by the ordinance as a political-institutional instrument for its regulation, proves fragile as for its implementation, due to the high cost for construction and operation. Other settings, previously built, can become part of the network, being a locus of care for these people.

## FINAL CONSIDERATIONS

The study now concluded has allowed us to know the peculiarities of the health care provided to deaf people who use the sign language, from their own perspective, with the aim of reflecting on the access, the humanized and comprehensive care, and on the right to health, in view of the proposal for implementation of the Network of Care for Disabled Persons.

The barriers to communication and information during the care for the deaf reveal the challenge to a humanized and comprehensive care due to a restricted communication. It is believed that sign language is one of the ways to effectively communicate with these users in health services. Even though the sign language interpreter is not decisive in guaranteeing quality care, they can improve it substantially, when well prepared, with the skills and competences required to act in this space.

Therefore, it is necessary to invest in the training of sign language interpreters intended to act in the various settings of the care network and, likewise, to encourage the training of health professionals who are already working in the SUS network. These strategies, combined with investment in the training of the health professional, even during the undergraduate program, with a focus on humanization, ethics, the organic, linguistic and cultural specificities of deaf persons, as well as on techniques that can facilitate the interaction between hearing professionals and deaf users, are crucial to enable the quality of the health interventions.

From the perspective of these informants, the health services have not yet been organized in order to meet their needs. Although they recognize legal achievements, there are still challenges to be overcome, which are mainly imposed by the attitudinal, communication and information barriers that occur in the interpersonal relationship, thus limiting the exercise of autonomy and freedom of choice, an important guideline for the functioning of the Network of Care for Disabled Persons. It is up to managers, health professionals, users and training institutions, supported by the inductive policies and the local reality, to organize health care lines for deaf people which consider the particularities revealed and effectively ensure the right to health recognized in the Citizen Constitution.

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