

Original articles

The perspective of deaf patients on health care

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ABSTRACT

Purpose: to learn the deaf people's perspective on the improvements needed in this population's health care.

Methods: an observational, cross-sectional study conducted with 124 deaf people who answered a semi-structured questionnaire to characterize the sample (age, sex, and means of communication) and collect answers to the open question: "Do you have any suggestion to improve the health care for the deaf?" – which was answered either in writing or in the Brazilian Sign Language (Libras). A descriptive analysis was conducted to characterize the sample, as well as a quantitative and qualitative content analysis (thematic-categorical), to identify categories and occurrence frequency of the content in the answers to the open question.

Results: the sample's mean age was 44 years (standard deviation 15, minimum 18, and maximum 70 years), 65% were women, and 78% used Libras to communicate. Most of the participants (83%) answered the open question in writing. Six theme categories were identified: 1) Needed improvements; 2) Communication barriers); 3) Health promotion; 4) Autonomy; 5) Achievements; and 6) Law.

Conclusion: the results reveal a need for improvements in the health care of deaf people. The perspective of the studied deaf population is based on their desire to gain autonomy, overcome communication barriers, and have access to information, aiming at health promotion.

Keywords: Sign Language; Unified Health System; Access to Health Services; Public Health; Speech, Language and Hearing Sciences

INTRODUCTION

Deafness is an invisible disability, especially regarding accessibility, as it does not require physical changes, as is the case of people with reduced mobility¹. However, deafness does require actions implemented to train health professionals to use, translate, and interpret the Brazilian Sign Language (Libras) and raise awareness in the population².

Deafness may impair communication and oftentimes become a barrier to communication between health professionals and deaf patients¹. This situation contributes to deaf people's low adherence to health services and to inadequate diagnoses, thus interfering with their quality of life^{1,3}.

In Brazil, the National Health Policy for People with Disabilities⁴, established by the Ministry of Health to include people with disabilities in all the services of the *Sistema Único de Saúde* (SUS, the Brazilian public health care system), was designed to formulate, follow up, and assess the health care actions to this population. These initiatives have been developed with guidelines such as the promotion of the quality of life, prevention of disabilities, comprehensive health care, improvement of information mechanisms, training the human resources, and organization and functioning of the health services⁴.

Complying with the guidelines of the Ministry of Health has been motivated by some actions on the part of the very government. It is essential to have professionals in the health services able to communicate in Libras with people with hearing loss. This is demonstrated by Law no. 10.436 of 2002⁵, which recognizes Libras as a legal means of communication of the Brazilian deaf people, and by Decree no. 5.626/2005, specifically in chapter VII, which regulates the said law. This decree ensures to people with a hearing loss the right to health in the SUS service network, receiving care from qualified professionals who can communicate in Libras⁶.

Moreover, in 2006 the Ministry of Health developed a booklet entitled "The Person with a Disability and the *Sistema Único de Saúde*"⁷. The document, guided by comprehensive health care, presents a series of information on the health-related rights of people with disabilities. Such comprehensive care includes the right to accessibility, whose goal is to provide a gain in autonomy with safety to a wider range of people with difficulties communicating, getting informed, and moving^{7,8}. To promote accessibility, the health services must be assessed regarding the attention given to the people with disabilities⁹. An important parameter in this assessment is the knowledge of the patient's perception of the attention they are given. A recent questionnairebased study analyzed the perceptions of 121 deaf people concerning their communicational process with primary health care professionals in the state of Rio de Janeiro. The data reveal that most of the deaf people reported insecurity after the visits to the doctor and that the bilingual deaf people were the ones that best understood their diagnosis and treatment⁹.

Knowing the user's perception has important contributions to approaches in administration planning strategies, decision-making in the health services¹⁰, and the development of actions that will help health professionals get better prepared to meet the patients' expectations.

The assessment of the health services is guided by three concepts: the quality of the structure (which refers not only to the physical setting but also the professionals who work at the health service); the process of the actions (which generally refers to the manner how the professionals develop their activities in terms of the relationship between them and the patients); and lastly, the results of the work (which reflect directly on the users' life)¹¹.

Hence, the assessment of the health services is extremely relevant for their realistic contributions¹¹, working as a vector to direct and plan the service, as it assesses the strategies used and the continuity or not of the actions. It is an important indicator to be considered when planning the actions, and a means to promote continuous improvement, providing quality care to the user¹².

Considering that the deaf users' experience at the health services and the perceptions, reflections, and expectations it triggers are elements that contribute to the assessment of these services, this study aimed to learn the deaf people's perspective regarding the necessary improvements in this population's health care.

METHODS

This is an observational, analytical, cross-sectional, quantitative and qualitative study, an integral part of a research project named "*COMUNICA*" (COMMUNICATE), approved by the Research Ethics Committee of the *Universidade Federal de Minas Gerais* - *UFMG* (Federal University of Minas Gerais), Brazil, under evaluation report no. 799.714.

The research project was developed in the context of a public outreach program interfacing with scientific research at the institution of origin. Its objective is to develop health promotion actions and raise awareness in future health professionals about the relevance of Libras in their training.

The research was conducted between April 2013 and May 2014 in two philanthropic institutions that offer support to the community of deaf people in the city where the institution of origin is located.

The sample comprised people with hearing loss who met the inclusion criteria: self-declared deaf or with a hearing loss, over 18 years old, attending or working at one of the two support institutions for the community of deaf people. All the participants signed the informed consent form.

A total of 124 volunteers participated in the research. The number of participants represents 25.62% of all those who are deaf or have a hearing loss and attend or work at either of the two institutions where the collection was made.

The data were collected with a recently published semi-structured questionnaire made up of three parts¹³. The said study investigated the satisfaction of deaf users with the care received at health services, based on data from the first and second parts of the questionnaire. The present research analyzed the answers to the open question: "Do you have any suggestion to improve the health care for deaf people?", which is in the third part of the questionnaire. Also, data on sample characterization were analyzed, encompassing sex, age, and means of communication they used, which is in the first part of the questionnaire.

The research was carried out in a separate room, either in the facilities of the philanthropic institutions or at the participant's workplace. A single meeting was held with the researcher, lasting approximately 15 minutes and using the interviewee's preferred means of communication: written, oral, or in sign language. The meeting was filmed to register the answers with accuracy and trustworthiness.

The collection procedure with the participants who used the sign language could be conducted in one

of the following manners, as they preferred: a) the participant read the questionnaire and answered it in writing; b) the researcher interpreted the questions into Libras and the participant registered their answer in writing; c) the researcher interpreted the questions into Libras, the participant answered in Libras, and the researcher registered the answers translating them from Libras to Brazilian Portuguese, always checking with the participant, in Libras, whether the registered answer was accurate. In all the cases, the researcher helped the participant during data collection, if they so required.

To analyze the answers to the open question given in Libras, there searcher and a sign language translator/ interpreter (SLTI) watched and translated the videos to ensure greater trustworthiness. If there was any divergence between translations, a second SLTI would make another translation. The reports written by the participants were fully typed – without correcting spelling or agreement mistakes – to be analyzed afterward.

The participants' (P1 to P124) data regarding their sex, age, and means of communication, as well as the manner how they answered the open question (in writing or signs), were submitted to descriptive analysis, conducted with the frequency distribution of the categorical variables and measures of central tendency (mean) and dispersion (standard deviation) of the numerical variable (age).

The open question was analyzed based on a qualitative and systematized approach, made with the thematic-categorical content analysis technique^{14.} The participants' answers were read, identifying repeated and mutually related content in the terms and expressions used in each one of them, thus defining the core ideas. These contents or core ideas were grouped into subcategories and/or categories related to a specific theme. The frequency with which each core idea occurred in the participants' answers 'answers was computed.

RESULTS

The studied population (N= 124) comprised participants 18 to 70 years old – mean age 44 years and standard deviation 15 years – most of whom were females (65%). Regarding the means of communication, 78% used Libras (Table 1).

Variables	N	%
Sex		
Females	80	65
Males	44	35
Age		
18-28	51	41
29-39	36	29
40-50	24	19
51-60	12	10
61-70	1	1
Communication		
Libras	48	39
Verbal	27	22
Bilingual	49	39

Table 1. Distribution of the participants (n=124) regarding sex, age, and means of communication

Caption: Libras: Brazilian Sign Language

Most of the participants (83%) chose to write themselves the answer to the open question, in which each participant presented their suggestions and perspectives about improvements on the health care for deaf people.

In the qualitative analysis of the answers to the open question, 18 core ideas were identified and grouped into six theme categories and their respective subcategories and/or core ideas. The subcategories were developed or defined based on one or more core ideas, according to the content extracted from the participants' answers. The theme categories, subcategories, and/or core ideas were the following: 1) Needed improvements: types of improvement, presence of an interpreter, assistance technology; 2) Communication barriers: difficulty communicating, attitudes of the health professionals; 3) Health promotion: speeches for the community of deaf people, training for the professionals; 4) Autonomy: accessibility, privacy, independence; 5); Achievements: hearing aid supplied by SUS, respect for people with a disability; and 6) Law: teaching Libras in basic and higher education, inspecting. Transcriptions selected by the researcher to represent the sample's answers, their categorization, and each core idea's occurrence frequency are shown in Figures 1 to 6.

Theme category	Subcategory	Core ideas	Transcription of the answers
Needed improvements	Types of improvement	Improved attention (N=5)	"Yes, need to improve attention in health, and have an interpreter in the field of health because nowadays people are not patient with deaf people. And the physicians learn libras to attend better the deaf people". (P120)
		Increased number of community health centers and professionals (N=7)	"More community health center. More physicians in all specialties". (P96)
	Presence of an interpreter	At public and private services (N=61)	"There should be more interpreter at the public and private places". (P73) "I need, I'm interested and would like if there were an interpreter in the doctor's office. And for the attendants too. It's very hard to communicate. There needs to be interpreter in these places". (P88)
	Assistance technology	Technological resources (N=2)	"I think the attention to deaf people should be given more importance like in my case I hear very little they have to speak more calmly or have a LED display to call us by name because I have always to ask someone to listen when they call me and then the physician says you didn't hear before knowing my problem but who knows already is polite it's hard when they don't know". (P5)

Caption: N: number of occurrences

Figure 1. Transcriptions of the answers under "Needed improvements", subcategories, and core ideas (continues)

Theme category	Subcategory	Core ideas	Transcription of the answers
	Difficulty communicating	Prejudice (N=2)	"I think it needs interpreter in the hospital. Because all the deaf people have a hard time communicate with physician. I too have already suffered prejudice because the people have no patience communicate and speak. My family doesn't know libras, so I sometimes go alone or with an interpreter. I would like that all hospital need help with disability it's important". (P48)
Communication		Difficulties with Portuguese (N=9)	"Each health center could have interpreter. There are difficult words in Portuguese. The interpreter needs to be together so we can understand clear and learn". (P49)
barriers	Attitudes of the health professionals when attending deaf people	Health professionals' impatience	<i>"It needs to improve more in the field of health and be more patient with the deaf people to understand them". (P16) "Improve the attention using special speech with deaf people.</i>
		(N=14)	Speak slowly and a lot of patience, if doesn't know try to use libras if necessary". (72)
		Increased vocal intensity (yelling) (N=2)	"People more patient in the reception, who can respect people with disabilities and specially me who am impaired listener, when I don't understand don't yell at me because it's embarrassing". (P8)

Caption: N: number of occurrences

Figure 2. Transcriptions of the answers under "Communication barriers", subcategories, and core ideas (continues)

Theme category	Subcategory	Core ideas	Transcription of the answers
	Speeches for the community of deaf people	Speeches on health for the deaf people (N=2)	"SUS should have libras interpreters, both in hospitals and in community health centers, should offer speeches on health to the community of deaf and hearing-impaired people". (P25)
Health promotion	Training for the health professionals	Offering courses and workshops in Libras (N=20)	"I wanted to improve that the physicians know libras and they need to give courses on libras to the health professionals". (P66) "Libras interpreters. Have workshops like health in Libras". (P77)
		Raise awareness in the health professionals to learn Libras (N=25)	"The ideal to improve the health attention to people with hearing loss would be to train the health professionals like for example a course on libras or hiring employees, interpreters, for the satisfaction and better benefit not only of the deaf people but also the health professional". (P113)

Caption: N: number of occurrences

Figure 3. Transcriptions of the answers under "Health promotion", subcategories, and core ideas

Theme category	Core ideas	Transcription of the answers
Thoma datagory	Accessibility (N=5)	"I would like that the attention (be) was priority for people with disabilities, that these attention was with clarity, where the people had accessibility with their communication. For example, deaf people when get to hospital reception or anywhere, some use only gestures others don't the receptionists most of the time don't understand, treat us bad. Like in my case I went to an appointment with the physician, I told I was hearing-impaired, these people they forget about us, I was paying attention, the time the physician, I waited my turn, it was hard, but I got his (physician) verbalization. So I would like, more accessibility to everyone". (P83)
Autonomy	Privacy (N=3)	"I think there is a lot to improve, because more qualified professionals are necessary, the physicians need to have an idea of libras for deaf people to have the privacy to go to the physician without a companion, so they can ask their questions, because it's not always good to talk to the physician with somebody around". (P122)
	Independence (N=8)	"We will get older and we need physician. We need interpreter to help us in the physician. Lip reading is difficult. To go to the physician, we need the friends or children. If the son is busy, is at school". (P1)
		"I think the people with a disability in general area little discriminated. Many times in the reception for ex. we meet nervous people that get us a little depressed specially in the few consultations I had at Sus. (not everyone) Need then be obligation use an interpreter. Because may times we can't go with company, and it's a type of independence too". (P6)

Caption: N: number of occurrences

Figure 4. Transcriptions of the answer sunder "Autonomy" and core ideas (continues)

Theme category	Core ideas	Transcription of the answers	
Achievements	Hearing aid supplied by SUS (N=1)	"In my opinion I think the prejudice with the deaf people changed a lot now we can consider we are all the same it in differs because there is the interpreter. Even the clinic that gives us the hearing aid we have. It's getting better and better". (P100)	
	Respect for people with a disability (N=2)	"I am partially hearing-impaired so far, the medical attention I consider good, as long as I have told the people my degree of disability. They attend us very well". (P4)	

Caption: N: number of occurrences

Figure 5.	Transcriptions of	of the answers	under "Achievements"	and core ideas
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Theme category	Core ideas	Transcription of the answers
	Teaching Libras in basic and higher education (N=1)	"They could give more importance to the deaf people, making a law in public schools and higher education, to learn sign language". (P124)
Law	Inspecting	"The professionals attend the patient well, in my opinion, what's missing is that the government, don't care about other people, and there's a lot to improve in health in general". (P91)
	(N=1)	"They need to inspect if the law is being obeyed there needs to be libras interpreter and the physicians and receptionists know libras". (P118)

Caption: N: number of occurrences

Figure 6. Transcriptions of the answers under "Law" and core ideas

DISCUSSION

The results of this study revealed that the communication barriers between health professionals and deaf people make comprehensive care more difficult and bring unsatisfaction to this population. This finding corroborates a recent study that analyzed the deaf people's perception of the communication process with the health professionals in the state of Rio de Janeiro and concluded, among other things, that the communication barriers discourage deaf people to seek health services⁹.

The present research, it must be said, was conducted at two support institutions for the community of deaf people, not directly related to health services. However, a study conducted¹³ with deaf people who received care in both the public and private health networks verified that both groups were not satisfied with the medical care. They reported that the means of communication used by the professionals and the presence of an interpreter were not effective and that strategies would need to be implemented to ensure these population's accessibility to health and its comprehensiveness.

Concerning the means of communication, 39% of the participants used only sign language – which reflects the need for either qualified interpreters or health professionals fluent in Libras, as reported in the answers transcribed under "Needed improvements".

The Libras interpreter is the professional qualified to translate and interpret the sign language into the country's oral language¹⁵. This professional is more often present in educational settings¹⁶. Despite the recognized importance of the Libras interpreter in the health context – which is also backed by law that requires their presence in the health services –, the access to this professional has not yet become a reality^{2,17}. This can be verified in the findings of the present research, as in most of the answers to the open question the participants reported the difficulties finding this professional available in health care and emphasized the importance of the interpreter as a mediator.

The presence of these professionals at the health care services may minimize the communication barriers¹⁸. On the other hand, many deaf participants of this research also reported feeling uncomfortable with their presence, fearing for indiscretion, and even the embarrassment of reporting about private

aspects in front of other people. These data are corroborated by previous studies¹⁹. It was also verified they preferred being attended by professionals who knew Libras to keep their privacy and independence – which is confirmed in the literature¹⁷. Moreover, under "Autonomy", the participants stated the importance of professionals who could communicate, thus dispensing with the need for a companion – which was also reported in a previous study¹⁹.

A strategy suggested by participants of this study to try and minimize this problem was to train health professionals in sign language. This very strategy has already been pointed out in a previous study¹⁷.

The participants also highlighted some attitudes of health professionals during deaf patients' visits that may contribute to diminish the communication barrier – e.g., speak calmly and slowly and not yell. Another striking aspect in the analysis of the answers to the open question was the report about the health professionals' impatience with the deaf people. A similar result was found in previous research⁹, which identified in deaf people the factors that could impair the communication with health professionals. For such communication to improve, the participants of the research suggested that they use simple words, look at the patient when speaking, not write when speaking, and simplify the terminology.

Another relevant point to mention is many professionals' mis belief that written language could be a means of overcoming the difficulties in health care. As mentioned in a literature review¹⁸, writing would be the option to interact with those who master the written language but not with deaf people, for whom Portuguese is a second language²⁰. The participants' reports included under "Difficulty with Portuguese" in the present paper corroborate this thesis.

For the deaf population to actually have access to health, there are still challenges to overcome. From the standpoint of the participants of this study, teaching sign language to listeners at regular schools may be a feasible strategy. However, it is believed that to achieve it, it would be necessary to train in Libras more professionals who work in preschool and elementary school²¹.

Despite the communication difficulties presented by the participants of the present study, they also mentioned achievements in recent years. For instance, under "Respect for people with a disability", they recognized that many professionals, when dealing with a person with a disability, seek strategies to meet their needs. In this sense, actions to raise awareness among health students, as reported in previous studies^{1,2}, contribute to better-quality health care and fewer frailty situations, which is also expected by the deaf population.

Another aspect mentioned in the answers to the open question refers to the health professionals' training in Libras, aimed at "Health promotion". This type of action is greatly important and depends, among other things, on public health policies and programs to improve the attention given and reduce situations of vulnerability in the population, which is also targeted by the deaf population. This expectation is corroborated by studies that describe the importance of training and qualifying the professionals as essential factors to meet the health needs and recognize the culture of deaf people^{22,23}, which could minimize the communication barriers²⁴.

The deaf patients' needs identified in this study can help structure new strategies or continue those that already have good results, contributing to better care for them and promote their health. They also point to the need for debates on the communication between deaf people and health professionals, which may result in proposals to be put into practice.

Another suggestion mentioned in this study to improve the health care for deaf people refers to health education aimed at the deaf population. It is thus verified that health literacy is necessary and should be discussed regarding the community of deaf people as well²⁵. Explaining about the functional systems of the human body and the health habits promotes knowledge, clarifications, and practical opportunities regarding the information received in the interaction with health professionals.

CONCLUSION

Given the findings, it was verified that, despite the requirements in the law, in the deaf people's perspective there is still a need for improvements in this population's health care.

To improve the quality of their health care, the population in the present study suggested: a) having an interpreter at the services to ensure their access to health; b) overcoming the communication barriers and promoting a more humanized care; c) implementing actions to train health professionals in Libras, thus, promoting health education initiatives and the deaf patients' autonomy.

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