Accessibility of adolescents with hearing impairment to health services

Acessibilidade do adolescente com deficiência auditiva aos serviços de saúde

Manuela Maschendorf Thomaz¹, Viviane Marten Milbrath², Ruth Irmgard Bärtschi Gabatz³, Vera Lúcia Freitag³, Jéssica Cardoso Vaz³

ABSTRACT
The aim of this paper was to identify difficulties and ease of access to health services by adolescents with hearing impairment from the perspective of their family caregivers. This is a qualitative study with the participation of 10 caregivers of hearing-impaired adolescents. The results show that caregivers seek health care services sporadically, in cases of illness and/or for regular consultations. The participants reported experiencing prejudice and indifference on the part of health workers at the health care services. Moreover, they stated the health workers have difficulty communicating with the hearing-impaired users, which violates the principles of the Unified Health System and leads to unsatisfactory consultations. It is concluded that the lack of preparation and confidence of health workers significantly hinder the quality and humanization of care since communication is the basis for human understanding.

Descriptors: Hearing loss; Adolescent; Health Services Accessibility; Nursing; Health Communication.

RESUMO
Objetiva-se identificar a perspectiva do cuidador familiar acerca das facilidades e dificuldades no acesso do adolescente com deficiência auditiva aos serviços de saúde. Estudo de abordagem qualitativa, no qual participaram 10 cuidadores de adolescentes com deficiência auditiva. Os resultados mostram que a busca pelos serviços de saúde ocorre esporadicamente, em casos de adoecimento e/ou consultas regulares. Os participantes relataram preconceito e indiferença vivenciados dentro dos serviços de saúde. Soma-se a dificuldade que os profissionais têm em comunicar-se com os surdos, ferindo os princípios do Sistema Único de Saúde e levando a consultas insatisfatórias. Conclui-se que a falta de preparo e a insegurança dos profissionais dificultam significativamente a qualidade e a humanização da assistência, uma vez que a comunicação é a base para o entendimento humano.

Descritores: Perda auditiva; Adolescente; Acesso aos Serviços de Saúde; Enfermagem; Comunicação em Saúde.
INTRODUCTION

Hearing impairment (HI) is the partial or total inability to hear sounds due to the absence of electrical stimuli to the brain. Children with HI may exhibit delays or alterations in speech. Moreover, they may be born with congenital HI or acquire it at the time of delivery, in the neonatal period or throughout their lifetime. A child without HI perceives very low sounds, from zero to 15 decibels (dB), whereas a child with HI may only hear or perceive sounds above 25 dB(11).

Globally, 278 million people have HI, which corresponds to 4.6%, according to the World Health Organization (WHO). Two-thirds of this population are in developing countries. The incidence of HI at birth is one to three out of every 1,000 live births. Currently, the WHO estimates that around 360 million people suffer from disabling hearing loss and 32 million of these sufferers are children(19).

In Brazil, according to the 2010 Census published by the Brazilian Institute of Geography and Statistics (IBGE), 9.7 million people or the equivalent of 5.1% of the population suffer from HI. Of these individuals, 2,147,366 people have severe HI, in which hearing loss ranges from 70 and 90 dB. About one million of this population are adolescents aged 19 or under(19).

Consequently, it is imperative to discuss issues concerning the accessibility of these adolescents to health services. However, despite the laws and policies to ensure people with disabilities have access to public health services and people with HI get adequate care and treatment, divergences are found in practice because health care primarily focuses on curative action and health workers feel unqualified to attend these populations(19).

Workers who provide care to adolescents must consider these users are going through a complex transition from infancy to adulthood, characterized by physical and psychological changes, identity formation and questions about life. Furthermore, adolescence encompasses issues such as bullying, sexuality, socialization and understanding about oneself(5), all of which can be harder to cope with in adolescents with HI.

The official language of deaf people is sign language (LIBRAS, in Brazil); however, hearing-impaired adolescents have difficulty communicating with health workers and, consequently, encounter problems while accessing health services and rarely receive humanized assistance, often leading to insecurity, mistrust and resentment during care(6,7). In this context, health care teams feel uncomfortable because they are unprepared to understand adolescents with HI, which prevents these teams from providing the necessary care(8). Effective communication is understood as a fundamental part of adolescent care and it is considered the basis for forming bonds and providing comprehensive care.

A search in the Virtual Health Library revealed gaps in the literature regarding this subject matter. Results showed health workers do not understand sign language and even children and adolescents with cochlear implants have difficulty communicating with health teams. Moreover, psychosocial difficulties and low self-esteem were also found among deaf people who use oral language(9).

Therefore, it is necessary to reflect on existing laws and their enforcement. Special attention is needed with adolescents since, in addition to all the dimensions of vulnerability they experience, they have a deficiency that hinders communication and often compromises their family and social relationships(10).

In this sense, health workers must be able to assist families in coping with the situation and stimulate the growth and healthy development of adolescents with HI, which modifies negative thoughts, reduces feelings of culpability and attributes new meanings to quality of life.

Consequently, this study aims to identify the perspective of the family caregiver regarding the difficulties and ease of access of adolescents with HI to health services.

METHOD

This is a qualitative study. Data were collected at a special needs school for the deaf in a municipality in southern Brazil. This school is a philanthropic institution funded through agreements with public authorities and community donations. It provides bilingual education for students with several degrees of deafness.

Ten main caregivers of adolescents with HI enrolled at the institution participated in the study. In this study, adolescents were considered individuals between the ages of 10 and 19, as established by the WHO. The criteria for inclusion were primary caregivers of adolescents with HI attending the special needs school. Caregivers who did not communicate verbally and those who cared for deaf adolescents with other associated pathologies were excluded.

Data were collected in November 2017 using individual semi-structured interviews recorded on an MP4 device and conducted at the school premises. The data were subjected to thematic analysis(11), according to the following six stages: familiarization with the data through transcription, reading and rereading; generation of initial codes by coding important characteristics; grouping of main themes, bringing together the relevant data for each potential theme; verification of themes according to the encoded extracts and generation of an analysis map; definition and assignment of names to themes; creation of the academic analysis report.

The ethical precepts of Resolution nº 466 of 12 December 2012 were observed and data were only collected after the project was approved by the Research Ethics Committee.
(CEP), opinion nº 2.333.560. Written informed consent was obtained from the participants, at which time they learned about the objective of the research, its risks and benefits and the guarantee of anonymity. The interviewees were identified with the letter “C” (Caregiver) followed by a sequential number.

RESULTS

The 10 participants were the mothers of adolescents with HI between the ages of 10 and 16. All the adolescents had severe deafness. One of the adolescents used a hearing aid and another adolescent had a bilateral cochlear implant. The results were divided into the following two categories: the search for health services; difficulties faced in the care provided by the health services.

The search for health services

It was observed that the caregivers sought the health services sporadically, in cases of illness, vaccination and/or regular follow-up and development monitoring consultations:

She goes when she has something, pain, or for a vaccine […] (C6).

When he’s got a fever, something like that, I take him (C7).

[...] vaccines when needed […] and when you see it is something that will not go away alone, a fever that is taking too long (C10).

The search for health services reflects some difficulties regarding access such as the precariousness of care related to the lack of professionals and the absence of a free demand for care:

A shortage of physicians; the most common problem is lack of health workers (C3).

The usual problem of having to stand in line at the early hours of the morning, and when you get there, they cannot always see you on that day […] we all have to deal with the difficulties, but, of course, his language is the biggest difficulty (C10).

According to these statements, deaf adolescents have the same difficulties when accessing health services as those faced by the general population. Furthermore, they must cope with difficulties communicating, which can increase their vulnerability.

Difficulties faced in the care provided by the health services

The difficulties confronted when receiving care at the health services include prejudice and indifference. According to the participants, health care workers classify these adolescents as incapable, debilitated and sick because of their hearing loss. From the perspective of the caregivers, this perception of deaf adolescents is linked to the lack of knowledge and preparation of health workers.

The nurses kept whispering […] thinking it strange that the boy next to us shouted the whole time and would not calm down while mine did not shout; then the other one said, “Oh, it must be because he is sick” (C1).

[…] and he [the health worker] looked at me really seriously and said, “But do the deaf have earache?” […] he was amazed that deaf kids can have an earache (C4).

The way she attended us was terrible, it was the only time I felt totally rejected by a doctor […] it seemed he did not accept his condition of being deaf and his inability to answer […] it was very fast, she asked and I answered for him and I thought she was very cold (C9).

The participants also stressed difficulties in relation to communication between the adolescents and the health workers and the lack of privacy during care.

[…] especially the language, conversation, communication; there is none (C8).

Difficultly communicating, you know, like, for example, now he knows LIBRAS and could very well communicate using LIBRAS and then there would be none (communication) if I do not interpret (C9).

According to the caregivers, the fact that the health workers have no knowledge of LIBRAS creates a distance between the user and the professionals, as information of the adolescent’s health condition must be transmitted, thus preventing autonomy and individualized treatment:

The doctor asks, I signal to her and she shows us […] where it is hurting […] but I am the one who does the interpreting for her, the doctor or the nurse does not communicate at all (C6).

During the consultation, I signal to the doctor to say what she is feeling […] then he examines something, but that is all (C8).

Therefore, the care provided is considered inadequate by the participants due to the lack of understanding that makes it impossible to know the real problem and prevents the deaf adolescent from understanding the adopted therapeutic approaches.
I think a person who knows LIBRAS, an interpreter [...] is lacking and should be provided (C2).

I think they should have a specialized person who knows LIBRAS, who knows how to talk to them, who knows how to understand them [...] (C3).

Health services should provide someone who knows LIBRAS; they should have them because a lot of children need them (C5).

An interpreter. First of all, an interpreter. For the future, at least, because I will not be able to take her but then I will know that place, that establishment has an interpreter who is able to understand her (C6).

In contrast, the presence of a health worker who knows how to communicate with the hearing-impaired adolescents positively affects the progress and outcome of care, revealing the importance of a minimal understanding of LIBRAS.

The difference in care [...] the doctor on duty knew LIBRAS, knew the basics of LIBRAS and managed to start a conversation with her [...] it was huge for her because someone understood her and that was great (C6).

I was surprised by the nurse who wanted to clean his foot, wipe it with saline solution and he would not let him, frightened and crying and the nurse started using sign language and you have no idea how that changed care, how it calmed him [...] (C10).

It is noted that the basic knowledge of LIBRAS favorably alters the outcome of care; however, as noted earlier, this situation is sporadic rather than a common practice in the daily lives of people with HI. In the following statement, C1 reveals the reality of many deaf people when they seek assistance at the health services.

I have never met a doctor, I have never met a nurse, I have never met anyone who knows LIBRAS in all these years. No one communicates with him (C1).

One of the solutions, as mentioned by the interviewees, is the presence of a LIBRAS interpreter at the health services when providing care for deaf adolescents. This professional would enable more effective communication and ensure the privacy of adolescents since they would not need a family member to translate their statements to the physician or nurse.

DISCUSSION
Access to health care is a right of all citizens and a duty of the state, according to the Constitution of the Federative Republic of Brazil of 1988. This right is further endorsed by the principles of the Unified Health System (SUS), which ensure universal unprejudiced access, comprehensive care, problem-solving capacity and equity in health services according to the needs of each individual[12].

Public social inclusion policies aim to expand health actions and guarantee all people receive care regardless of their restrictions, thus promoting equity. Some examples of the National Policy of Persons with Special Needs are Law nº 10.436 that regulates LIBRAS and ensures adequate care and treatment for people with disabilities in public services, Law nº 10.098 that guarantees access to communication and the Statute of Children and Adolescents that confers protection to the health of this population[4].

Receptive assistance in health care must include qualified listening to help solve problems or minimize the problem situation brought by users. The establishment of bonds is crucial to ensure humanized care and follow-up, when needed[13].

Although receptive assistance improves understanding of the needs of users and facilitates access to health services through dialogue and the promotion of health care actions, many users, when seeking care, report their discontent with the shortage of health workers, difficulties in scheduling appointments, the limited number of consultations offered and the long waiting times. These problems are the greatest barriers to health care[14].

In addition to the participants of this study, the general population also faces obstacles to access, such as the irregular coverage of the Family Health Strategy (FHS), geographical barriers, difficulties scheduling appointments and the lack of referrals and counter-referrals[15].

A study showed that deaf patients are more likely to use emergency services than the non-deaf population. Deaf users who communicate through sign language are a minority population with poor access to health services, such as primary care, due to communication barriers[16].

The deficiency in communication has created gaps in primary care that increase the vulnerability of this population and impair care.

The absence of communication between patients and health workers calls for a mediator for dialogue, which results in a breach of confidentiality. Interaction is also considered unsatisfactory since patients misunderstand the words of health workers, leading to compromised communication during consultations and the consequent inability to respond to the problem situation appropriately given the lack of active participation in the discussion and in decision making[17].

Moreover, in the health service itself, the deaf are confronted with the prejudice and indifference of health professionals who, like society, classify the deaf as incapable, debilitated and sick due to their hearing loss. This fact reveals
the lack of knowledge and preparation of health workers to
deal with deaf users and the inequality and obstacles faced by
this population in the pursuit of health care(7).

The lack of knowledge of professionals about deafness
also affects assistance. Health workers have reported feeling
embarrassed, underqualified and incapable of attending
users in a satisfactory manner and providing care according
to the needs of the deaf community due to inefficient
communication(18).

A study showed that nursing professionals do not use
successful communication strategies with deaf people in
health care because they lack relevant knowledge and skills
and may feel fear, impotence, frustration, shame and denial.
This fact interferes with the quality of the care provided and
leads to misunderstandings, errors in decision making and
mistrust on the part of users and their families(9).

Communication in health care is the main means of
creating bonds and identifying the needs that bring the
person to the service. Thus, the lack of professionals with
knowledge of LIBRAS can lead to the distancing of users
with HI since information regarding their health condition
will be passed on to a companion rather than directly to
those who need and seek the service, thus neglecting
other principles of ethics, such as patient autonomy and
individualized treatment(19).

The deaf community does not use health services in the
same way as non-deaf people because their health-related
knowledge is acquired by other means due to communication
barriers, thus compromising the comprehensiveness and
humanization of care and favoring social exclusion(18).

Nursing professionals often lack the knowledge or tools
needed to provide care to deaf people. Therefore, they should
be trained in communication strategies, such as the use of
sign language, to adequately provide care to this population.
This would preserve the right of HI users to confidentiality,
reduce the stress caused by the presence of third parties
during consultations and ensure their full and satisfactory
inclusion. The lack of training and awareness on the part
of health workers when providing care to hearing-impaired
or visually-impaired patients affects assistance to the point
that these users avoid seeking health care and prefer not to
participate in health promotion activities(9).

Thus, it is extremely important to include such
an indispensable communication tool as LIBRAS in
undergraduate health care programs and train health workers
to interact appropriately so they may give priority to quality
dialogue and humanized care and meet the demands of the
hearing-impaired population(20).

Universal and comprehensive care, access to information
and equity are rights, according to the guidelines of the
SUS, that are also violated by the inability of most health
workers to communicate with hearing-impaired users.

In this perspective, humanizing care is extremely important
to ensure the needs of users are understood and to reduce
obstacles during assistance, limitations in dialogue and the
stigmatization of care for the deaf population(21).

Providing a LIBRAS interpreter significantly improves
the execution of care; similarly, professionals who have learned this
sign language would enhance performance when exchanging
information with deaf users(22). In addition to adolescents, all
people with HI should be observed, without generalizations,
since impairment is individualized and manifests itself in the
emotional, psychological, social and physical dimensions of
people’s lives(23).

CONCLUSION

The results of the present study show hearing-impaired
users are confronted with prejudice when using the health
services, as well as health workers who are unprepared to
provide care to this population. Deaf adolescents encounter
the same difficulties when using the health care services
as those encountered by the general population, such as
long waiting times, difficulty in scheduling consultations,
reduced number of available appointment slots and shortage
of health care staff. In addition, these users and health
workers have difficulties communicating, revealing the
social inclusion of the hearing-impaired, as established by
law, is not yet a reality.

The lack of preparation and confidence of health workers
significantly hinder the quality and humanization of care
since communication is the basis for human understanding.
The presence of a sign language interpreter can facilitate
dialogue and ensure satisfactory care. Moreover, care provided
by health workers who have minimal knowledge in LIBRAS
is considered satisfactory.

Therefore, it is necessary to reflect on the quality of
services provided to deaf adolescents and on the importance
of including special needs in health care education in order to
construct a practice that includes the study of LIBRAS and
aims to humanize care and ensure effective communication.
A proposal to reorganize the health service would be the
implementation of an on-call sign language interpreter
by area of coverage, who can assist during consultations
and enable efficient dialogue. Furthermore, the creation of
practical manuals with LIBRAS signs for health care workers
may also help.

The limitation of this study was the population, composed
of the caregivers of hearing-impaired adolescents; a study on
the perspective of the adolescents with HI would provide
additional insight into the studied subject. In addition,
investigating the health workers who provide care for this
population would support the creation of strategies to cope
with the involved difficulties.
REFERENCES


© 2019 Universidade Federal de Goiás
This is an open access article distributed under the terms of the Creative Commons license.