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Literature revision about the attendance of deaf patient by health professionals

REVISÃO DE LITERATURA SOBRE O ATENDIMENTO AO PACIENTE SURDO PELOS PROFISSIONAIS DA SAÚDE

REVISIÓN DE LA BIBLIOGRAFÍA SOBRE LA ATENCIÓN DE LOS PROFESIONALES DE SALUD AL PACIENTE SORDO

Neuma Chaveiro¹, Maria Alves Barbosa², Celmo Celeno Porto³

ABSTRACT

The purpose of this systematic literature review is to analyze and identify the communication between deaf patients and health professionals, as well as to investigate the care offered. The computerized databases were used for data collection, using the keywords *paciente* (patient), *surdo* (deaf person), and *comunicação* (communication). The results were grouped in three categories: communication, health professional education, and legal aspects. The communication category deals with communicative barriers, written language and the presence of the interpreter. In the second category, the focus is on the education of the professionals in relation to the deaf community. The third category reports the legal aspects involved in caring for deaf patients. The review showed that there are communication barriers between deaf patients and health professionals, and that health care is a challenge for both. It also emphasized that there is a need for education regarding the deaf patients.

KEY WORDS

Communication.
Deafness.
Sign language.
Professional-patient relations.

RESUMO

O objetivo deste estudo de revisão sistemática da literatura é analisar e identificar a comunicação entre o paciente surdo e o profissional da saúde, bem como investigar a assistência oferecida. Foram utilizadas as bases de dados informatizadas para a coleta de dados, tendo como palavras-chave os termos *paciente*, *surdo* e *comunicação*. Os resultados foram agrupados em três categorias: comunicação, formação dos profissionais da saúde e aspectos legais. A categoria comunicação aborda barreiras comunicativas, linguagem escrita e a presença do intérprete. Na segunda categoria, o foco está na formação dos profissionais referentes à comunidade surda. A terceira categoria relata os aspectos legais no atendimento ao paciente surdo. A revisão mostrou que há barreiras de comunicação entre paciente surdo e profissional da saúde, e que o atendimento é um desafio para ambos. Ressalta também a necessidade de formação sobre o paciente surdo.

DESCRIPTORES

Comunicação.
Surdez.
Linguagem de sinais.
Relações profissional-paciente.

RESUMEN

El objetivo de este estudio de revisión sistemática es analizar e identificar la comunicación entre el paciente sordo y el profesional de salud, así como investigar la atención brindada. Fueron utilizadas las bases de datos informatizadas para la recolección de datos, siendo las palabras claves *paciente*, *surdo* y *comunicación*. Los resultados fueron agrupados en tres categorías: comunicación, formación de los profesionales de salud y aspectos legales. La categoría comunicación trata sobre las barreras comunicativas, el lenguaje escrito y la presencia del intérprete. En la segunda categoría el enfoque fue dado a la formación de los profesionales con respecto a la población surda. Finalmente, la tercera categoría referida a los aspectos legales en la atención al paciente sordo. Esta revisión demostró que existen barreras comunicativas entre el paciente sordo y el profesional de salud. Asimismo, la atención es un reto para ambos, destacando la necesidad de invertir en la formación de profesionales para prestar cuidados al paciente sordo.

DESCRIPTORES

Comunicación.
Sordera.
Lenguaje de signos.
Relaciones profesional-paciente.

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INTRODUCTION

The IBGE Census (Brazilian Institute of Geography and Statistics/2000) reveals that there are 24.5 million people with disabilities in Brazil, which accounts for 14.5% of the population. Of them, 16.7% show hearing impairment, that is, there are 5,735,099 deaf individuals in Brazil. Taking the annual population growth into consideration, nearly 93,295 deaf children are born each year⁽¹⁾.

In the past, deafness was something that could bring prejudice. Deaf individuals were regarded as worthy of pity and victimized by society and even their own family⁽²⁾. However, this behavior has been changing and nowadays it is discussed by professionals of several fields of knowledge.

Helen Keller, who had been deaf-blind since she was 19 months old, considered that being deaf is worse than being blind. Being blind isolates the individual from the world, but being deaf isolates the individual from other people. She was born in 1880, wrote several books and gained notoriety due to the book titled *The World I Live in*, published in 1914⁽³⁾.

It should be pointed out that deafness leads to many consequences. The deaf individual, however, has spatial-visual means of communication that is as effective as the oral-auditive, used by listeners. The deaf individual's communication problem is not organic. It is social and cultural.

The relationship of health professionals with patients who have a normal hearing level is established by verbal contact. This mechanism is not often used by deaf patients who resort to sign language to communicate⁽⁴⁾. It belongs to spatial-visual modality, since the signs are shared by the eyes and its production is performed by the hands in space. It is recognized as a language by Linguistics. It is regarded as being a natural language and it is not considered a deaf-related issue or a language pathology⁽²⁾.

Sign languages are present in the five continents, but are not universal. Each one has its own grammar structure. With the sign languages, it is possible to express any complex, subtle or abstract concept. Sign languages are linguistic systems as highly-structured and complex as oral languages. They are neurologically structured in the same cerebral areas⁽⁵⁻⁶⁾.

For the deaf individual, the means of communication used by the surrounding milieu is not a facilitating resource to interact with the world. It stands as an obstacle that needs to be overcome in order to effectively reach the social world⁽⁷⁾.

With all the hardships involving relationships between deaf individuals and healthcare professionals, two ques-

tions emerge: since communication is such an important tool in the several healthcare procedures, how do the professionals interact with deaf patients? The communication barriers that emerge when two different languages are in contact compromise the quality of assistance provided to the deaf population? This study intends to answer these questions by investigating the scientific production. The study aims at identifying and analyzing the studies on communication between deaf patient and the health professional, and also the assistance provided to the deaf population.

METHOD

This is a systematic literature review whose search was performed in January 2007 at the Health Virtual Library (BVS). The following databases were used: LILACS, International literature (MEDLINE), Health in Adolescence (ADOLEC) and Nursing Database (BDENF).

In the MEDLINE database, we opted to review the 1996-2006 period. The structured research was used through a basic form with the terms *patient*, *deaf* and *communication* as keywords. Overall, 65 articles were found.

The deaf individual's communication problem is not organic. It is social and cultural.

In the LILACS, ADOLEC and BDENF databases, we opted to review the literature without restricting the period. There was a structured research using the basic form with same terms previously used. In LILACS, 5 articles were found and 1 of them was also present in MEDLINE. In ADOLEC and BDENF, 2 articles were identified in each. They were also present in LILACS and MEDLINE.

All the 70 articles were read so as to identify their proposed objectives. After that, 16 articles from MEDLINE and 2 from LILACS were excluded, since they looked at therapeutic and surgical aspects. 51 articles were identified with the same objective.

Internet websites of organizations working with the deaf community were also searched. The data originated three thematic categories: communication, healthcare professional education and legal aspects.

RESULTS AND DISCUSSION

The data were grouped in three thematic categories: communication, healthcare professional education and legal aspects. In the first category (communication), we selected articles on communicative barriers, written language, non-verbal communication and the presence of sign language interpreters. In the second category (healthcare professionals), we selected articles that looked at the importance of programs and the education of professionals and students regarding identity and sociocultural aspects

of the deaf community. In the third category (legal aspects), we selected articles that reported the legal aspects when it comes to treating the deaf patient.

The 51 articles selected in accordance with the objectives proposed in this study were grouped in different categories and may be included in more than a category.

Table 1 - Distribution of articles published on MEDLINE and LILACS, according to the categories established - São Paulo - 2007

Indexation source/categories*	Communication	Education	Legal Aspects
MEDLINE	35	20	12
LILACS	2	1	-
Total articles*	37	21	12

*One article is included in more than one category

Despite the significant number (51) of articles published in the studied period regarding the communication between deaf patients and healthcare profession-

als and the assistance provided to this population, the Brazilian scientific production is incipient, with only 2 articles.

Table 2 – Distribution of published articles on deaf patient care by health professionals, according to the year, country, and language of publication - São Paulo - 2007

Country - Language / Year	1992	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	Total
USA	-	4	2	-	6	5	-	5	1	3	2	2	30
England	-	1	1	1	2	1	-	1	-	1	3	1	12
Germany	-	-	-	-	-	-	-	-	1	-	1	-	2
Scotland	-	-	-	-	-	1	-	-	-	-	-	-	1
Switzerland	-	-	-	-	-	-	-	-	-	-	-	-	1
Saudi Arabia	-	-	-	-	-	1	-	-	-	-	-	-	1
France	-	-	-	-	-	-	1	-	-	-	-	-	1
Brazil	-	-	-	-	-	-	-	-	-	-	-	1	1
Portuguese	-	-	-	-	-	-	-	-	1	-	-	-	1
Spanish	1	-	-	-	-	-	-	-	-	-	-	-	1
Total	1	5	3	1	8	9	1	6	3	4	6	4	51

Note: MEDLINE – According to year (1996-2006) and the country of the publication LILACS - According with the published language, the country is not informed.

In the results, shown below, it is important to point out that the literature review served as guide to develop the text, in the aforementioned thematic categories.

Communication

Communication is an important tool for healthcare professionals concerning diagnosis and treatment. Verbal instructions related to varied procedures rely on them. The result may be compromised by the lack of understanding of the involved parts⁽⁸⁻¹⁰⁾.

Researchers show the need of better communication between healthcare professionals and deaf patients. However, communication with deaf people remains negligenced in the

health systems^(8,10-11). Therefore, non-verbal language is a communication resource that ought to be known and valued in the health action practices⁽¹²⁾. Even when sign language is unknown, it is fundamental to interpret its suprasegmental aspects that include gestures, facial and body expressions⁽¹³⁾.

Non-verbal communication is extremely important when assisting patients, enabling healthcare excellence. The professional that is aware of it captures the non-verbal signs conveyed by patients, favoring interaction^(12,14).

By comparing deaf individuals and listeners, it is possible to see their specificities, which are fundamental to intervene with deaf patients. It is not possible to generalize the deaf individuals as though they were all the same,

given that there are differences regarding sensorial and communicative aspects⁽¹⁵⁾.

The factors that should be considered in this population include the level of hearing loss, the time when the hearing impairment started, the linguistic preferences and also psychological and sociocultural questions⁽⁷⁾.

Some studies fail to look at deaf individuals as distinct people, not observing their diversity. Each patient is unique and generalizing and channeling the studies as though they were identical is, indeed, naïve. In order to avoid such attitude, it is necessary that the healthcare professionals stop considering only the disease and start providing care to a person who is sick and unique⁽¹⁶⁾.

The presence of interpreters in the healthcare services is thought to solve all the communication problems between patients and healthcare professionals. However, this is not always true. The interpreters' performance may lead to some improvement, but it is not decisive for high-quality assistance⁽¹⁷⁾. Deaf individuals cherish the presence of the interpreter, but with some reservation: distrust, embarrassment to be exposed before the interpreter, commiseration and difficulty in finding available interpreters^(14,18).

As deaf individuals often do not show visual problems, written language could be an alternative. But, actually, it is not. For them, the oral-auditive language in the country is like a second language, and therefore, learning it is difficult. Hence, the written language is not the way to improve assistance⁽¹⁴⁾.

The communication success with deaf patients depends on the individual characteristics of the deaf person. Regarding their communicative needs, they can be grouped in three categories:

1. **People with hearing impairment**, who still benefit linguistically from verbal code.
2. **Deaf people who communicate orally**, who, in turn, may be divided into two groups: a) adults who lost hearing; b) deaf children who were brought up in an oral orientation.
3. **Deaf people who communicate through sign language**, who lost hearing before three years old, that is, during the period of verbal language acquisition and had the sign language as a means of communication⁽⁹⁾.

The deaf population is a heterogeneous group and includes people with varied levels of hearing loss. They resort to several means to communicate and belong to different cultures⁽⁸⁾. When assisting deaf individuals, it is important to know these differences, which will influence the established attachment.

The communication barrier that hinders or prevents the interaction between deaf individuals and healthcare professionals can only be overcome when other interaction forms are found. This is the only way to guarantee good quality assistance⁽⁵⁻⁶⁾.

Health care professional formation

There are many drawbacks when it comes to assisting deaf individuals, especially linguistic difficulties, lack of trust in the listeners' world and lack of access to preventive measures⁽¹⁹⁾. They are also regarded as having low intelligence, and compared with mental patients. Deaf individuals are not familiar with healthcare assistance. They do not have proper information about HIV/AIDS and attend doctors' offices less frequently when compared with listeners^(8,20-21).

The consultation with the deaf patient may be sporadic, but the challenge for healthcare professionals is much more than the specialized services can provide. Coping with people who do not share the oral language and show their own culture is not routinely taught. Therefore, the professionals may not be prepared to meet the deaf patient⁽²²⁻²⁴⁾.

For the healthcare professional, an effective communication with clients leads to better quality assistance^(5,25-26). Thus, it is urgent to train healthcare professionals to treat these patients. Also, in order to assure access to healthcare, it is advisable to study communication methods, deaf culture, sign language fundamentals, lip reading and how to behave in terms of assistance to deaf people^(19,21,23,27-28).

Studies show that, in order to work with minorities, it is essential to understand their cultures. The deaf population who uses sign language is linguistically and culturally a minority group^(24,29), but most courses in the health area characterize deafness as a pathological condition, not considering the deaf population as a minority group⁽²³⁾.

The deaf community is composed by people who use sign language as their first means of communication. They feel that they belong to the deaf culture, with unique features, language and social rules. They differ from other disabilities due to their communicative process, not to physical handicaps⁽⁶⁾.

Culturalist studies on deafness have chosen the sign language as a prime factor in the deaf culture. With the support of Linguistics, sign language is the deaf community's mother tongue, with all the features that grant it the status of language. Thus, there is the establishment of political frontiers of the deaf cultural movement⁽²⁹⁾.

Legal Aspects

With an inclusive orientation, the World Health Organization showed in 2003 a new model to evaluate disabilities, the International Classification of Functioning – ICF. Before 2003, people with disabilities were evaluated by the parameters of the International Classification of Diseases - ICD. The ICD is assessed under the perspective of sickness and the ICF is assessed based on functionality. The adoption of ICF does not discontinue the use of ICD. It should be mentioned that Brazil agreed, along with other countries, about the commitment to officially adopt this new reference starting in 2004⁽³⁰⁾.

Thanks to the complexity of the doctor-deaf patient relationship, it is important to know its underlying legal resources, and also understand the deaf person's identity and the cultural factors that characterize the deaf community. These are the differentials in the quality services provided to this population⁽³¹⁾.

After countries had officially acknowledged the sign language as the deaf community's natural language, the health care professional is required by law to assure effective treatment to the deaf population^(10-11,32). The decree no 5.626, of December 22, 2005, that regulates law no. 10.436/02 – Brazilian Sign Language Law – LIBRAS, points out the Chapter VII that guarantees the right to health of deaf individuals or people with hearing impairment. In this decree, chapter 25 states that:

A year after the publication of this decree, the Public Health System and the companies that are in conjunction with public services, in order to fully include deaf individuals or people with hearing impairment in all social levels, must guarantee full attention to health in all the complexity and medical specialties:

IX – assistance to deaf individuals or people with hearing impairment in the Public Health services and companies in conjunction with public services, by skilled LIBRAS professionals or translation and interpretation; and

X – Supporting training and education of professionals in the public services to use LIBRAS and its translation and interpretation⁽³³⁾.

Likewise, the Ministry of Health elaborated a manual titled *People with Disabilities and the Public Healthcare System*, for doctors, nurses and other healthcare professionals. It proposes the social inclusion of people with disabilities as a general goal. The following piece of information contained in the manual deserves to be highlighted:

The full attention to health, focused on people with disabilities, presupposes specific assistance regarding their condition, that is, service strictly compliant with their disabilities, as well as assistance to diseases and problems common to any citizen⁽³⁴⁾.

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The approval of the Federal Law no. 10.436/02 stems from the struggles of sign language users in the Brazilian deaf community. The public institutions are responsible for providing programs to educate healthcare professionals when it comes to assisting and treating deaf patients⁽³⁵⁾.

Sign language is not a choice; it is the deaf community's language. The access to information in this language is not well defined, since there are barriers that prevent the understanding of diseases and decision related to health^(31,36). A study carried out in the United States found that deaf patients prefer to be assisted by doctors who master the sign language or by deaf doctors^(31,36).

CONCLUSION

The literature review showed that the communication barriers between deaf patients and health care professionals may cause the assistance provided to be at stake, and also influence the diagnosis and treatment.

The studies have demonstrated that it is fundamental to know the cultural and linguistic specificities of the deaf community so as to favor interaction between patients and professionals, significantly reducing their discomfort during consultations.

The reading of the scientific articles showed that the deaf patients' assistance is a challenge to health care professionals and deaf individuals. Verbal communication is not a resource to facilitate the deaf people's interaction with the world. In contrast, it is an obstacle that should be overcome to effectively reach the social world.

Research suggests, especially in academic institutions, that there is need of studies regarding deaf patients' assistance. Being with a deaf person does not imply only in perceiving hearing impairment, but also sociocultural and legal aspects.

Further studies related to deaf patients' assistance in the healthcare area are likely to be carried out, due to the reduced number of publications in Brazil.

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