

Nursing Care for People with Intellectual Disability and Deafness: Integrative Literature Review

Larissa Bornholdt¹, Eglon Pauli², Lucia Regina da Silva Barros³, Leila Mariza Hildebrandt⁴,
Marinês Tambara Leite⁵, Vera Lucia Freitag⁶

¹Nursing student. Federal University of Santa Maria/ Palmeira das Missões Campus

²Nursing student. Federal University of Santa Maria/ Palmeira das Missões Campus

³Family Health Strategy Nurse by the Municipal Health Department of Três Passos. Specialist in Public Health, Education

⁴PhD in Sciences, Professor of the Nursing Course at the Federal University of Santa Maria/Palmeira das Missões Campus

⁵PhD in Gerontology, Professor of the Nursing Course at the Federal University of Santa Maria/Palmeira das Missões Campus

⁶Nurse. PhD student in Nursing. Federal University of Rio Grande do Sul

Abstract: *To analyze the published scientific production about nursing care for people with intellectual disabilities and deafness. Integrative literature review with search in the Virtual Health Library Platform, in Portuguese, English and Spanish. Three hundred and seventy three articles emerged for analysis, and nine articles composed the sample. Difficulty on the part of professionals to establish effective communication with people with intellectual disability and deafness was evidenced. The studies indicated the importance of sign language training to favor the interaction. Most scientific productions are related to the care of hearing impairment, with a shortage of articles addressing the care of intellectual disability.*

Keywords: People with disabilities; Nursing; Care; Deafness; Assistance

1. Introduction

Individuals with special needs form a heterogeneous group, affected by several types of deficiencies such as physical, sensorial, intellectual and mental deficiencies. Health actions directed to this population must consider their various needs. Follow-up and care are determinant in this process and should start as soon as the disability is identified; otherwise, the development and quality of life of these individuals can be compromised, influencing their insertion in different social spaces. The prevention of diseases and the promotion of health of these people are linked to the determination of resources and, above all, the public policies of this sector⁽¹⁾.

According to the World Health Organization⁽²⁾, one billion people live with a disability; this figure corresponds to one in seven people in the world. Nevertheless, there is a lack of knowledge about this information and this leads to the invisibility of this population stratum, ultimately contributing to the incipient planning of public policies aimed at improving the care provided to these people⁽²⁾. When considering these data, flaws in the health care for this population contingent become noticeable in daily life.

Intellectual disability is characterized by deficits in mental abilities such as reasoning, planning, thinking, academic learning, and problem solving ability. The cause of the deficiency may be related to an acquired lesion, such as severe head trauma or genetic syndromes such as Down syndrome, Lesch-Nyhan syndrome, Rett syndrome, San Phillip syndrome, and often associated with autism spectrum disorder⁽³⁾.

In turn, hearing deficiency can be defined as the partial or total loss of the ability to detect sounds attributed to genetic causes or lesions in the hearing system. In contrast, anyone lacking ability to hear sounds is considered deaf. It is emphasized that in this study the two terms will be used as synonyms to refer to individuals with deafness⁽⁴⁾.

Nursing is a profession that aims to provide care with troubleshooting and to this end, it needs to have a global view of its clientele. However, it has been observed that nursing professionals are little prepared to act in scenarios involving people with special needs⁽⁵⁾. The care provided by the nursing team is based on the promotion, maintenance and recovery of the basic needs of the individuals, especially when their physical and mental integrity is compromised.

When nurses treat people with disabilities, their role is to ensure assistance at the various levels of complexity, applying specific methods and therapies according to the demand⁽⁶⁾. Thus, providing comprehensive care involves a set of factors that includes knowledge, skills and attitudes to allow the patients to have a minimum of independence and autonomy⁽⁷⁾.

In this perspective, this study has as guiding question: How is it for the nursing team to provide care for persons with special needs related to intellectual disability and deafness that seek health services? The study aims to analyze the published scientific production about nursing care for people with intellectual disabilities and deafness.

2. Materials and methods

In order to meet the objective of this study, an integrative literature review was carried out. This research method is based on the following stages: identification of the problem and elaboration of the guiding question of the research; determination of the inclusion and exclusion criteria; definition of information and categorization of studies; analysis of the studies included in the review; interpretation of the data found; and finally, presentation of the results obtained⁽⁸⁾.

The bibliographic search was carried out through the Virtual Health Library Platform (VHL-HEALTH) with access to the following databases: LILACS (Latin American and Caribbean Literature in Health Sciences), BDNF (Nursing Database), MEDLINE (Medical Literature Analysis and Retrieval System Online) and IBICS (Spanish Bibliographical Index of Health Sciences). The study was conducted in the second half of April 2018, through the joint use of Descriptors in Health Sciences - DeCS (“*peessoas com deficiência*” AND “*enfermagem*” AND “*cuidados*”). After these terms were translated into English according to MeSH: Disabled Persons, Nursing, Nursing Care. These descriptors were also combined with the Boolean operator AND. The filters used were full text available in English, Portuguese or Spanish, without time limit. The inclusion and exclusion criteria are listed below in the Table 01.

Table 1: Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Research articles Reflective articles Experience reports Manuscripts published online with full texts available and free in electronic format. Published in Portuguese, English or Spanish. No limitation of time	Repeated articles, and articles that are not related to the theme investigated. Literature review articles, theses, dissertations, books, book chapters, ministerial documents, scientific technical reports and annals of congresses or conferences.

3. Results

The use of DeCS in the databases generated a result of 373 studies. From these, 364 did not meet the inclusion criteria, after reading the abstract, and were excluded. The final sample consisted in a total of nine articles for analysis. The results of the bibliographic search, distributed per database, is shown in Table 02.

Table 2: Results of bibliographic search, according to database and descriptors

Database	Descriptors	Number of articles	Selected articles
BVS	“ <i>Pessoas com deficiência</i> ” AND “ <i>Enfermagem</i> ” AND “ <i>Cuidados</i> ”	373	6
LILACS	“ <i>Pessoas com deficiência</i> ” AND “ <i>Enfermagem</i> ” AND “ <i>Cuidados</i> ”	47	1
BDNF	“ <i>Pessoas com deficiência</i> ” AND “ <i>Enfermagem</i> ” AND “ <i>Cuidados</i> ”	33	1
MEDLINE	Disabled People” AND “Nursing” AND “Nursing Care”	281	0
IBICS	“ <i>Pessoas com deficiência</i> ” AND “ <i>Enfermagem</i> ” AND “ <i>Cuidados</i> ”	08	1

The use of the descriptors listed by the researchers is justified by the objective to expand the search in the Virtual Health Library Platform through the use of the DeCS “*peessoas com deficiência*”, and not “*Surdez*” because a limited number of publications was found using this word. The purpose of this research was to include individuals with intellectual disability and deafness, and therefore the DeCS used detected a greater sample of articles for analysis.

After selecting the manuscripts to be included in this review, they were read in full length and the information was organized through a previously elaborated instrument that included: Identification of the article, reference, objective(s), type of study, place where it was conducted, and main results. These data can be seen in Table 03.

Table 3: Information of the selected articles

Article	Article reference	Objective (s)	Type of study	Place	Main Results
A1	Temane A, Simelane L, Poggenpoel M, Myburgh CPH. Lived experiences of student nurses caring for intellectually disabled people in a public psychiatric institution, <i>Curationis</i> . 2016; 39(1), 1601.	To explore and describe the experiences of nursing students in caring for people with intellectual disabilities in a public psychiatric institution.	Exploratory, descriptive and contextual qualitative research.	Africa	Five topics emerged from the data. Nursing students experienced a profoundly disturbing impact on their whole being when they provided care for people with intellectual disabilities; they developed a sense of compassion and a new way of seeing life. They also experienced the need for certain physical, mental, and spiritual needs.
A2	Bronwyn H, Sabrena L, Kathleer M, Nadeera S, Kaely B, Bronwyn D. Supporting communication for children with cerebral palsy in hospital: Views of community and hospital staff, <i>Developmental Neurorehabilitation</i> , 2014; 17 (3): 156-166.	We intend to investigate the points of view of the health team and the nursing team in a joint effort to support the communication of children with cerebral palsy (CP) and complex communication needs (CCN) in the hospital.	Qualitative research	Australia	The participants reported having active roles in supporting infant seating, mobility, equipment, mealtime management and psychosocial needs, but not in supporting infants in communication at the hospital. The participants described several environmental barriers to support the augmentative and alternative communication (AAC) of children in a hospital and suggested a number of strategies to alleviate the difficulties of bedside communication.
A3	Dantas TRA, Gomes TM, Costa TF, Azevedo TR, Brito SS, Costa KNFM. Communication	To analyze the communication between the nursing team and	Qualitative research	Brazil	It was evidenced that the nursing team has difficulties in establishing communication with people with hearing impairment, because they do

	between the nursing team and people with hearing loss. Rev Enferm UERJ, 2014; 22 (2): 169-74.	people with hearing impairment in a teaching hospital in the municipality of João Pessoa - PB.			not know the Brazilian Sign Language (LIBRAS). For this reason they use strategies such as: lip reading, mimics, writing and the intermediation of companions. As suggestions for improving communication, the inclusion of courses on training and qualification in LIBRAS was mentioned.
A4	Aragão JS, Magalhães IMO, Coura AS, Silva AFR, Cruz GKP, França ISX. Access and communication of deaf adults: a voice silenced in health services. J. res. care Online, 2014; 6 (1): 1-7.	To investigate the access and communication of deaf adults in health services.	Descriptive study	Brazil	It was verified that 75% of the deaf people access the medical service and 88.9%, the dental service, and the public institutions are the most accessed (53.1%). The main factors that motivated 25% not to seek health services were: they do not need the service (88.8%) and they have no one to accompany them (44.4%). All the deaf people reported difficulty in communicating with health professionals, and the most frequently used alternative as the help of a relative (86.1%).
A5	Machado DA, Figueiredo NMA, Tonini T, Miranda RS, Oliveira GMB. Sign language: how the nursing staff interacts to take care of deaf patients? J. res.: fundam. care. online 2013; 5(3):283-292.	To identify how professionals of the nursing team of a university hospital interact to provide care for deaf clients.	Qualitative research	Brazil	Twenty-one (57%) reported never having provided care for deaf clients. Sixteen (43%) nursing professionals had already provided care to deaf clients; 12 (46.15%) made reference to use of mime; 4 (15.38%) mentioned the use of lip reading; 8 (30.77%) mentioned the use of writing; 1 (3.85%) mentioned the use of drawing; and 1 (3.85%) mentioned the help of an interpreter to communicate with deaf clients.
A6	Merrifield, RGN. Meeting the needs of people with a learning disability in the emergency department. International Emergency Nursing, 2011; 19 146-151.	This article aims to provide a better understanding of the risks associated with hospital care for individuals with learning disabilities, as well as the wider range of issues that may affect health care.	Reflective article	Not specified	Emergency nurses will regularly meet people with learning disabilities on a day-to-day basis in their work. Going to in the hospital and especially in the emergency department can be very problematic for people with learning disabilities. For a number of reasons, the health, safety and well-being of this group of patients can be seriously compromised.
A7	Bentes IMS, Vidal, ECF, Maia, ER. Perception of deaf people about health care in a medium-sized municipality: a descriptive-exploratory study. Online Brazilian Journal of Nursing. 2011; 10 (1).	To know the perception of deaf people about the health care offered in health services, as well as the difficult and facilitating aspects faced while seeking care.	Qualitative descriptive exploratory research	Not specified	The following categories were found as the main facilitating and difficult aspects presented by the subjects: dependency on the companion; communicative process in relation to the service and professionals; management of service provision; and professional training.
A8	Cruz OM, Pérez RMC, Jenaro RC. Nursing and disability: an integrative perspective. Index Enferm [Internet]. 2010; 19 (2-3): 177-181.		Reflective article	Mexico	Disability is a growing phenomenon associated with demographic, epidemiological and lifestyle changes, as well as technical and scientific advances in health. Its understanding within the social model (increasingly alienated from the biomedical model focused on disability and focused on the health area) is growing stronger each day.
A9	Pendergrass KM, Nemeth L, Newman SD, Jenkins CM, Jones EG. Nurse practitioner perceptions of barriers and facilitators in providing health care for deaf American Sign Language users: A qualitative socio-ecological approach. J Am Assoc Nurse Pract. 2017; 29 (6): 316-323.	To examine the perceptions of nursing professionals of facilitating barriers in the provision of health care for deaf users.	Qualitative research through semi-structured interviews using the SEM (Socioecological Model).	Mississippi	Barriers were identified at all levels of the SEM (socioecological model). The professionals preferred interpreters to facilitate the visit but were unaware of their role in ensuring the achievement of effective communication. A professional sign language interpreter was considered a last resort when all other alternatives failed. Gesturing, writing notes, reading lips and using a family member as interpreter were all considered facilitating aspects.

Of the analyzed articles, one was published in 2017, one in 2016, three in 2014, one in 2013, two in 2011, and one in 2010. In relation to the authorship of the articles, two were produced by nurses and psychologists, five by nurses, one by physicians and another had no specification of authors.

Regarding the place of study, 33.33% of the articles were developed in Brazil, 22.22% in North America, 22.22% had no specification of origin, 11.11% were produced and published on the African continent, and 11.11% in Australia.

Regarding the methodological options used, the majority used the qualitative method (66.66%), followed by reflective articles (22.22%), and descriptive studies (11.11%).

The analysis of the selected publications resulted in the elaboration of two themes: Nursing care for people with intellectual disability and Nursing care for people with impaired hearing. The literature review found that most of the manuscripts were related to the investigation of the care provided by healthcare professionals to clients with hearing impairment and highlighted the scarcity of productions overarching the care of the nursing team regarding intellectual disability with the descriptors used for this study.

4. Discussion

Nursing care for people with intellectual disability

We observed in the studies that there is difficulty in communication between health professionals, including of the nursing team, and people with disability as reported in articles A2 and A3. It is worth mentioning that communication is essential to provide qualified assistance and must be established since the patient's admission until hospital discharge because the process of hospitalization generates stress and emotional exhaustion to patients and their relatives, requiring support from the professionals involved in the care.

In the study A2, nurses pointed out parents as a fundamental source of support in the interaction with disabled people and cited the use of communication strategies for pain assessment, such as the use of laptops, portable games, internet images printed and placed next to the bed to facilitate communication between the staff and the patient.

On the other hand, a group of nurses (A2) showed a preference for not having the presence of parents when it comes to the post-anesthetic recovery unit because in case of children with disabilities, these may not cooperate when in the presence of a relative. However, nurses from medical and surgical clinics (A2) reported this same fact as negative and stressful, indicating the importance of the presence of parents during the hospitalization.

Although there are controversies about the presence or absence of parents during hospitalization, most of the studies analyzed indicated the need of a family member being present because they believe that the interaction without these relatives becomes difficult and sometimes stressful both for the patient and for the professional.

When it comes to communication skills and understanding, the manuscript A6 exposed that individuals with disabilities may feel fearful and isolated when exposed to unknown environments, as it is the case of emergency units. This is so because such event involves unpredictable places with diverse demands, and this can compromise the capacity of the disabled person to communicate and understand.

In this context, it is up to the professionals who provide care to understand that individuals are different and have their own history, their qualities and difficulties in a particular way, and each one has his way of experiencing adverse events⁽⁹⁾. This occurs with people with intellectual disabilities in relation to the situations to which they are exposed. The care offered to these people, including from the nursing team, should encompass the subjective aspects of each one, as well as the special needs presented. This is demonstrated in an example in Ireland that had clinical nursing specialized in intellectual disability to care not only for these people, but also for their families, workers, members of the multidisciplinary team, and external agencies⁽¹⁰⁾.

A survey reported that 35% of participants who had some degree of disability reported difficulties in understanding and listening to what health professionals said. This suggests a sort of unpreparedness of this professional category to meet the demand of this population when it comes to the use of communication resources, as well as greater availability of time for this action⁽¹¹⁾.

However, the difficulty of communication between patients and professionals implies a lower search for health services by people with disabilities. This can compromise the quality of life of these individuals, generate changes in team - patient relationships, and affect the trust in the professionals, as well as adherence of the patient to treatment⁽¹¹⁾.

The understanding of disability and the Systematization of Nursing Care (SNC), as emphasized in article A8, represents an opportunity to legitimize the nursing work as a social profession involved with the demands and inclusion of people with disabilities in society. Thus, in this perspective, the nursing work does not represent an attempt to extinguish the prejudice against this population stratum.

The manuscript A6 highlights that the difficulties encountered in the provision of care for disabled people are caused by three problems: lack of knowledge and understanding of health professionals regarding the needs of disabled individuals; vulnerability of these individuals; and the presence of complex needs associated with a disability. The lack of qualification and knowledge in the care of these patients generate actions that are usually unsatisfactory, both for the team and for the patients. In this situation, there are frustrations for both sides, because the professionals feel limited and the patients do not feel that are cared for (A6).

The manuscript A1 mentions the feeling experienced by nursing students while provided care for children with disabilities. They reported sadness, anxiety and emotional overload. They also mentioned the discomfort implied in working with disabled people who have a different physical appearance and expressed personal learning with appreciation of their level of health after having come in contact with these patients, due to their deformities and difficulties brought about by the disability. Furthermore, providing care to people with disabilities left the students insecure about becoming parents, fearing they may have children with similar characteristics.

In addition, it is evident the growing lack of interest of health institutions, as well as professionals, shown by a constant transference of responsibility from the professional to the hospital institution, from the institution to the academic training, and so on. The professionals also showed that they are aware of the difficulties linked to care, but had little interest in seeking enhancement in order to improve their daily practice. It is, thus, identified that institutions have little concern with vocational training with regard to care for people with disabilities (A3).

There is evidence of the imminent need for changes in the training of professionals, especially nurses, in order to provide humanistic and reflective care based on the principles of the Unified Health System, which includes comprehensiveness, universality and equity⁽¹²⁾.

Nursing care for people with impaired hearing

Regarding the care for hearing impaired users, a study reports the barriers encountered by nursing professionals, attributing them to the lack of knowledge or little knowledge of Sign Language. The professionals prefer to have the help of an interpreter to mediate the communication. They also mentioned lip reading and writing as strategies used to establish communication in the absence of interpreters (A9).

The interaction between health professionals and disabled patients is composed of communication barriers that compromise the establishment of bond and the offered assistance, with possible interference in the diagnosis and treatment. Furthermore, the study indicates the importance of offering programs to train professionals to provide adequate care⁽¹³⁾.

Other authors identified that, during consultations, when disabled people were accompanied by a relative, communication occurred among the listeners (companion and health professional), while the hearing impaired person was usually not involved in the process. In these cases, the loss of the privacy and protagonism of the hearing impaired person is frequent⁽¹⁴⁾.

Also, with regard to communication between the nursing team and people with hearing impairment, the article A3 mentions that this is an important and irreplaceable tool for understanding the needs of the people, being essential in qualified care. However, professionals express impediments to establishing communication with these patients, attributing the lack of preparation and training, because they do not have knowledge of their language. Associated with this, the lack of knowledge of Brazilian Sign language (LIBRAS) by professionals, and the unavailability of interpreters to mediate relationships also limit the provision of adequate care.

In the study A4, it was verified a difficulty of hearing impaired people to access the health services, as well as to communicate with the professionals. Data from this research indicate that 75% of deaf people sought medical care and 88.9% dental care. Regarding the main factors that motivated the search for these services, 44.4% of them were

unsuccessful to access the service because they had no one to accompany them and 100% mentioned having difficulties communicating with health professionals. Thus, this research indicates the need for improvements in the health care of this population, including nursing care, with emphasis on non-verbal communication. For this, the study indicates that one of the possibilities is the reformulation of the pedagogical projects of the vocational training courses, giving space to focus on the assistance to these individuals (A4).

It was evident that, due to the difficulty of being understood, hearing impaired people often give up seeking health services, and the lack of preparation and lack of alternative strategies for verbal communication is an aggravating factor in this process, leaving people with deafness countless times without receiving quality care.

In this same perspective, the manuscript A5 mentions the lack of preparation of the nursing team to deal with deaf clients, since the professionals do not know LIBRAS. This condition limits the implementation of the SNC provided to this segment. The employment of the SNC in the care and assistance, according to COFEN Resolution n° 272/2002, repealed by resolution n° 358/2009, predicts that this activity is exclusive to nurses, in the identification of health/illness situations and in the provision of services that encompass promotion, prevention, recovery and rehabilitation of individuals, families and community health⁽¹⁵⁾. However, it is still necessary to recognize the difficulties in implementing the SNC when it comes to people with disabilities.

The greatest difficulty in communication is mentioned when professionals are conducting medication guidelines and identifying symptoms mentioned by the hearing impaired people⁽¹⁶⁾. It is known that this fact can be attributed to the lack of knowledge of the professionals and this generates discomfort for the deaf users and sometimes leaves nurses uncomfortable in providing assistance.

As an aid to establish communication, it is recommended that during the consultations, nurses use the touch of hands, arms or shoulders, because these gestures are considered to denote affectivity and attention, facilitating non-verbal communication. This study reinforces that this professional category is not prepared to establish therapeutic communication with blind people, which is similar to what occurs with hearing impaired users⁽¹⁷⁾.

Communication, according to article A7, occurs unsatisfactorily and is permeated by barriers that compromise the autonomy of the individuals, hampering the creation of link and troubleshooting. It may also interfere in the diagnosis, treatment and prevention of diseases. There are also other obstacles when hearing impaired people seek health services, including queues, the distance traveled to reach the service, and the waiting time. As a resolution, study A7 points out as one of the possibilities the continuing education of health professionals, with a view to providing qualified care, geared to the needs of the users.

The lack of preparation of health professionals and of the service itself is related to difficulties in non-verbal communication, short time for consultations, lack of patience

and understanding, feelings of exclusion and discrimination, and lack of interpreters. This may interfere with diagnosis and treatment⁽¹³⁾. In the same sense, it is necessary that health professionals have knowledge about other means to communicate, learned in subjects of regular courses, specialization courses or programs of continuing education developed at hospitals⁽¹¹⁾.

It was possible to observe in all the studies the difficulty to establish communication with hearing impaired users, and that this is often cited as a hindrance to troubleshooting and effective care. Moreover, most study participants prefer to be accompanied by interpreters or family members who understand better their forms of expression than to employ other communication strategies such as: gestures, writing, and lip reading. It was also evident the lack of training in Sign Language, which further hinders the interaction between professionals and deaf people.

5. Conclusion

We conclude that it is essential to qualify health professionals working at all levels of complexity, be it basic, outpatient or hospital care, in order to provide effective and resolute assistance. It is understood that people with a disability are human beings who have particularities and preferences as well as needs.

Thus, the difficulties encountered can be minimized through intervention strategies, collaborating in the care provided and reducing the prejudice and exclusion of this population stratum.

It is worth mentioning that the studies analyzed focus on hearing impairment; fewer studies approached intellectual disability, although this is also routinely present in individuals who access health services. Because of this limitation, we suggest to carry out more studies related to nursing care for people with intellectual disability and deafness to allow a greater attention to this population and the qualification of professionals who provide care.

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aging, adult health, nursing, research, gerontology, geriatrics, old age and the elderly.



Teacher at the University of Cruz Alta (UNICRUZ). PhD student in Nursing at the Federal University of Rio Grande do Sul (UFRGS) by the Graduate Program in Nursing.

Author Profile



Larissa Bornholdt Graduated in Nursing from the Federal University of Santa Maria, Campus Palmeira das Missões / RS. Participation as a scholar by the Program of Tutorial Education (PET - MEC), from 2015 to 2018. Scholarship FIPE 2018.



Eglon Pauli Graduate student in nursing at the Federal University of Santa Maria / Palmeira das Missões Campus. Scholarship for Scientific Initiation FIPE 2018.



Nurse of the municipal municipal of Tres Passos. Specialization of pedagogical training in professional education in the health area by fiocruz, post graduation course - collective health graduation: emphasis in sanitarianism at the level of specialization area of knowledge: collective health.



He is currently a teacher with the exclusive dedication of the Federal University of Santa Maria / Campus Palmeira das Missões / RS. She has experience in Nursing, with emphasis in Nursing, working mainly in the following subjects: nursing, mental health, elderly health and group practice.



Teacher at the Federal University of Santa Maria (UFSM / RS) - Palmeira das Missões Campus. He works in the Graduate Program in Gerontology at UFSM. Tutor of the PET Group Nursing UFSM / Palmeira das Missões Campus. She has experience in Nursing, with emphasis on Gerontology, working mainly on the following topics: human