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REVIEW ARTICLE

Nursing care for people with disabilities in Primary Health Care

Atención de enfermería a personas con discapacidad en Atención Primaria de Salud

Cuidado de enfermagem às pessoas com deficiência na Atenção Primária à Saúde

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Abstract

Objective: to analyze the nurse's care for people with disabilities in Primary Health Care. Method: Integrative literature review guided by the following question: What is the role of nurses in caring for people with disabilities in Primary Health Care? The search was carried out in the databases: Database in Nursing, Latin American and Caribbean Literature in Health Sciences, PubMed that includes the Medical Literature Analysis and Retrieval System Online, Thesis Bank of the Coordination for the Improvement of Personnel Level Superior and Virtual Library of the Scientific Electronic Library Online; articles published in the period from 2008 to 2017. Results: Eleven studies were included in the selection, which after analyzing three categories were constructed: barriers to communication, barriers to access and barriers to understanding disability. Conclusion: It became evident that the inclusion of people with disabilities in health services is still marked by numerous challenges.

Descriptors: People with Disabilities; Primary Health Care; Health Communication; Patient Care Team; Nursing

Resumén

Objetivo: analizar la atención de enfermería para personas con discapacidad en Atención Primaria de Salud Método: Revisión integral de literatura guiada por la siguiente pregunta: ¿Cuál es el papel de las enfermeras en el cuidado de personas con discapacidad en Atención Primaria de Salud? La búsqueda se realizó en las bases de datos: Base de datos en Enfermería, Literatura Latinoamericana y del Caribe en Ciencias de la Salud, Pubmed que incluye el Sistema de Análisis y Recuperación de Literatura Médica en línea, Banco de Tesis de la Coordinación para la Mejora del Nivel de Personal Biblioteca Superior y Virtual de la Biblioteca Científica Eletrónica en línea; artículos publicados en el período de 2008 a 2017. Resultados: Se incluyeron once estudios en la selección, que luego de analizar tres categorías se construyeron: barreras para la comunicación, barreras para el acceso y barreras para comprender la discapacidad. Conclusión: se hizo evidente que la inclusión de personas con discapacidad en los servicios de salud aún está marcada por numerosos desafios.

Descriptores: Personas con Deficiencia; Atención Primaria de Salud; Comunicación de Salud; Equipo de Asistencia al Paciente; Enfermería

Resumo

Objetivo: analisar o cuidado do enfermeiro às pessoas com deficiências na Atenção Primária à Saúde. Método: Revisão integrativa de literatura norteada pela seguinte questão: Qual o papel do enfermeiro no cuidado às pessoas com deficiências na Atenção Primária de Saúde? A busca foi realizada nas bases de dados: Banco de Dados em Enfermagem, Literatura Latino-Americana e do Caribe em Ciências as Saúde, PubMed que engloba o *Medical Literature Analysis and Retrieval System Online*, Banco de Teses da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior e Biblioteca Virtual da *Scientific Electronic Library Online*; artigos publicados no período compreendido entre 2008 a 2017. Resultados: Onze estudos foram incluídos na seleção, que após analisados construiu-se três categorias: barreiras na comunicação, barreiras de acesso e barreiras na compreensão da deficiência. Conclusão: Evidenciou-se que a inclusão das pessoas com deficiência nos serviços de saúde ainda é demarcada por inúmeros desafios.

Descritores: Pessoas com Deficiência; Atenção Primária à Saúde; Comunicação em Saúde; Equipe de Assistência ao Paciente; Enfermagem

Introduction

Disability is a condition that results in long-term impairment of a physical, mental, intellectual, or sensory nature, which, in interaction with various barriers, compromise full and effective participation in society on equal terms with other people[1].

Study[2] on the self-reported prevalence of disabilities in Brazil, 12.4 million people were affected, that is, 6.2% of the population, with no difference between men and women. Visual impairment showed a higher proportion among the investigated disabilities, about 7.2 million people, intellectual disability was 0.8%, physical disability was 1.3%, and hearing impairment, the prevalence was 1,1%.

Although studies on demographic indicators of the health conditions of people with disabilities are scarce in Brazil[3], the impact of disability on these people's lives can cause difficulty in socializing, changes in lifestyle, physical adaptations, resulting in several health problems.

Primary Health Care (PHC), specifically the Family Health Strategy (FHS), is an organization model that intervenes in this context, as it is considered universal access, the gateway to the health system and the narrower level of care among health professionals, the disabled person and their family, which implies the need to comply with the principles of the Unified Health System (SUS) of universality, comprehensiveness and equity and seek strategies for the better care of these people[3].

In this way, the nurse must favor access for people with disabilities, accept complaints and seek solutions from the multiprofessional team, or when necessary, refer to other services, forming a network of interconnected care. In addition, the professional must be able to manage, supervise, plan, organize, develop, and evaluate actions according to the needs of each one[3,4].

The growing demand for people with disabilities and their singularities has led to the need for more inclusive care practices and the training of staff to align behaviors so that the needs of people are better received in health services. Thus, this study contributes to strengthen the actions of the Chronic Conditions Extension Program: innovative care. Thus, the objective of the study was to analyze the nurse's care for people with disabilities in Primary Health Care.

Methodology

It is an integrative review, a method that includes the analysis of significant research that support the resolution and improvement of clinical practice, in addition to identifying gaps in knowledge that need to be filled with new studies. For the methodological rigor of the study, six steps were taken[5]. In compliance with the first stage, the following guiding question was formulated from the PICo strategy: What is the role of nurses in caring for people with disabilities in Primary Health Care? It was considered P corresponds to the population: nurses, I: interest: people with disabilities, Co: Context: primary health care[6].

In the second stage, the following inclusion criteria were adopted: articles in Portuguese, English and Spanish, published in full, with the abstracts available in the selected database, which focused on nursing in the care of people with disabilities, published in the period from 2008 to 2017, including the year 2008 in this search, as it corresponds to the publication period of the National Policy for People with Disabilities. And as exclusion criteria: letters, editorials, experience reports, case studies, dissertations, and theses.

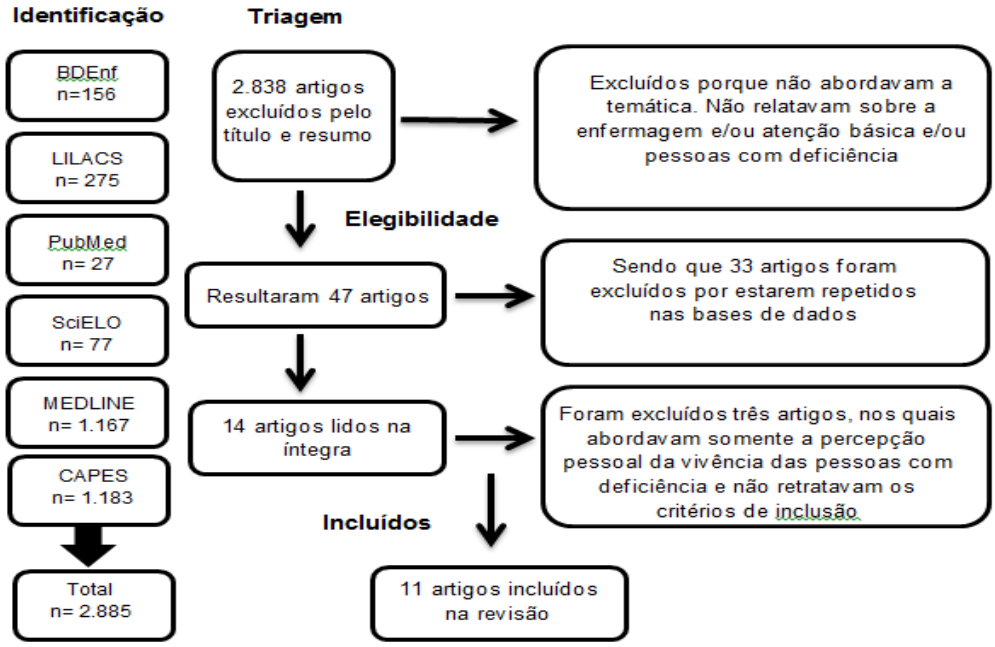
Then, the search for articles was carried out from October to November 2017, in the available electronic databases: Nursing Databases (BDENF), Latin American and Caribbean Literature in Health Sciences (LILACS), and National Library of Medicine National Instituteof Health (Pubmed) portal that includes MEDLINE, digital libraries (CAPES Thesis Bank), Scientific Electronic Library Online (SciELO) virtual library, through the Library's Health Sciences (DeCS) descriptors Virtual Health and English-language descriptors Medical Subject Headings (MeSH): "Disabled people", "Primary health care", "Nursing (Nursing)" and their correspondents in the Spanish language, using the Boolean operator “AND” between descriptors.

In the third stage, the abstracts were evaluated and the productions that met the previously established criteria were selected for this study and read in full. To obtain the data, an instrument validated by Ursi and Galvão[7] was adopted to extract information: year of publication, language, authorship, study objective, method, results, conclusions, and levels of evidence[6].

In the fourth stage, the information was analyzed by reading the selected articles in full. The data were organized and categorized. The fifth stage consisted of interpreting the results and assessing the role of nurses in caring for people with disabilities and possible recommendations for practice, based on their conclusions.

In the sixth stage, the review / synthesis of the knowledge produced on the role of nurses in caring for people with disabilities was elaborated[5]. Figure 1 shows the process of the articles selected in this integrative review.

Figure 1. Flowchart of identification, screening, eligibility, and inclusion of articles for the integrative review, from 2008 to 2017. Alfenas, MG, Brazil, 2018.



Source: Adaptation of Flow Diagram of the selection process of articles of the integrative review, according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyzes (PRISMA).

Results

Of the 11 articles, it was found that in relation to the methodological design, three (27.5%) were integrative reviews, two (18%) descriptive / qualitative, two (18%) qualitative, one (9%) descriptive, three (27.5) descriptive / exploratory / qualitative. As for the levels of evidence, two (18%) were classified at level V, with a systematic review of descriptive / qualitative studies, nine (82%), level VI, descriptive / qualitative studies.

Regarding the language of the studies, 10 (91%) were published in English and one (9%) in Portuguese, however, all were developed in Brazil. As for the authors, 10 (91%) belonged to the Nursing Department or Schools and one (9%) was authored by the medical field. Chart 1 presents the articles in relation to the title, author, year of publication, country, type of study, databases, and levels of evidence.

Chart 1. Characteristics of the studies included in the review in relation to the title, author, year of publication, country, type of study, databases, and levels of evidence. Alfenas, Minas Gerais, Brazil, 2018

Title	Author	Year	Country	Study Type	Data base	Levels of Evidence
Assistance to the person with Parkinson carrier in the context of family health strategy	GALVÃO et al.	2016	Brazil	Descriptive, qualitative exploratory	Capes	VI
Nursing care to patients in primary care in hemodialysis	CASTOLI; GARCIA; HARTWIG	2016	Brazil	Qualitative	Capes	VI
Nursing consultation to deaf people: a contextual analysis	ARAUJO et al.	2015	Brazil	Integrative Review	LILACS	V
Care of children with a chronic condition in primary care: challenges to the healthcare model	DUARTE et al.	2015	Brazil	Descriptive, qualitative exploratory	Capes	VI

Communication with people with hearing disabilities: an integrative review	MIRAND; SHUBERT ; MACHADO	2014	Brazil	Integrative Review	LILACS	VI
Acessibilidade de idoso com deficiência física na atenção primária.	GIRONDI et al.	2014	Brazil	Qualitative, descriptive	LILACS	VI
The accessibility of children with disabilities to primary healthcare services	ROSÁRIO et al.	2013	Brazil	Descriptive, qualitative exploratory	Capes	VI
The no-care of patients with spinal cord injuries in primary care: bioethical challenges for health policies	FRANÇA et al.	2012	Brazil	Qualitative, descriptive	BDENF	VI
Physical disability in the elderly and accessibility on primary health care: integrative review of the literature	GIRONDI ; SANTOS	2011	Brazil	Integrative Review	BDENF	V
Symbolical violence in the access of disabled persons to basic health units	FRANÇA et al.	2010	Brazil	Descriptive	Capes	VI
Disabled people in primary healthcare: professionals' discourse and practice in a healthcare teaching center	OTHERO; DALMASO	2009	Brazil	Qualitative	LILACS	VI

From the analysis of the results, a synthesis of knowledge was built into three categories, namely: barriers in communication, physical / architectural barriers, and barriers in understanding disability.

Discussion

Communication barriers

Communication is a basic instrument of nurses for the therapeutic process of care, as it produces dialogicity, empathy, understanding of the other, humanization[8,9], for bringing relationships closer and understanding subjectivities[8], the socio-cultural context and the needs, so that qualified care can be attributed10. Still, as it is a profession practiced in a team, one must value, understand and master the different forms of communication[11].

However, reality has shown that people with hearing impairments are the most difficult in society when compared to people with other disabilities and those who challenge and overcome the greatest existing failures, as they do not have the possibility to expose their doubts and concerns , besides being mistakenly compared with mentally disabled[12].

Although universal and equal access is provided for in Decree No. 6,949 of 2009[13], the Statute of Persons with Disabilities[1] and the principles of SUS[14], health services are not prepared to serve these people, as health professionals do not have the necessary training to use different communication strategies, which makes actions in this area still incipient.

The Disabled Person's Statute recommends the presence of a Translator Interpreter of Libras (TILS), interpreter, professional who understands processes, models, strategies, translation, and interpretation techniques[15], because it contributes effectively to communication. However, these interpreters may not be health professionals, which impairs the person with deafness to express their needs, especially in an intimate forum[16]. As well as, the presence of a family member, because the disabled person finds it difficult to express themselves and create a bond with the professional, which corroborates for an ineffective medical and nursing consultation[12].

In this logic, nursing consultations have shown weaknesses due to the lack of training for other languages, such as the Brazilian Sign Language (LIBRAS), the disadvantageous working conditions, the negative feelings that transpose the service, the difficulties in understanding both. parts and contextual conditions represented by public policies[1,17].

In view of this reality, the competence of the nurse must be expanded, so that the best approach to those with some disability becomes possible [3].

Thus, to minimize communication barriers, professionals see using some communication tools that enable the understanding of the disabled person. Among these are written verbal communication, communication via visual devices, presence of a family member or companion, the use of gestures that they trust to be appropriate to convey to people with disabilities what they are trying to expose, in addition to verbalization, touch and reading facial / body expressions[18]. The inclusion of simulation with

sensory experiences in the disciplines is recommended, considering that the training of professionals contributes to qualified assistance and the adhesion of people with disabilities to health services[19].

Although research on non-verbal communication is carried out, studies related to the effective communication of the health team with people with disabilities are still incipient, specifically of people with deafness.

The existence of barriers makes it difficult for nurses to propose care actions that meet the different needs of these people. The implementation of public policies, the valuation of the unusual and the concern with the unequal as a way of changing concepts and paradigms can contribute to strengthen professional practice, as well as the inclusion of mandatory subjects such as Libras in undergraduate courses[1].

Access barriers

Accessibility is the ability to connect people, places, and possibilities, causing limitations to be reduced, ensuring people's access to health services[20-21].

In Brazil, accessibility for people with disabilities is provided for in Decree 3298/99, by Law No. 10,098 / 2000, in Technical Standard NBR 9050 of the Brazilian Association of Technical Standards (ABNT), in the Statute of people with disabilities, in the principles of SUS and in the Humanization Policy, mainly related to ambience, which is the treatment given to physical space, understood as a social, professional and interpersonal relations space that should provide welcoming, resolutive and human attention and be meeting places between people[22]. The NBR 50 addresses the conditions and standards of regulated measures to provide the most appropriate conditions for access to public roads and urban architecture[23].

Accessibility is approached in studies from different perspectives, such as geographic access, which is the path taken by the patient from his home to the Basic Health Unit, added to the travel time. It is permeated by the lack of safety supplies in traffic, plus the absence of visual signs with the location of the health service, presence of unevenness or lack of sidewalks, trees, debris on the access path, car parking in front of the ramps of access and lack of public transport[24].

In health units, the reality experienced by users is very similar to that of public roads, which is due to the lack of access ramps, lack of handrails on the stairs, safety bars in toilets and slippery floors; which contrasts with that recommended by NBR 9050[23]. The flawed urban fabric, together with the health service, has flaws that harm not only people with disabilities, but the population as a whole, since everything that affects free access, shows it as an indicator of health risk[24,25].

These barriers prevent Primary Health Care from acting as a gateway for this clientele to the health service, which compromises people's functional access, triggering frustration, low self-esteem, impacts on behavior and difficulty in socializing. It is up to the professional to respect diversity, making these people members of society, free from discrimination and prejudice[26].

A study carried out by nurses with people who had difficulty accessing the health service found that physical disability was the main difficulty, even among those people who had alternative means of transport, as dependence on third parties is created, especially in the absence of support tools[27].

It is important to make people as active agents in the defense of health and for that, it is necessary for nurses to broaden their conception of the preventive purposes of the practice to a vision of purpose and more comprehensive actions, consistent with integrality in health. One possibility for changing the practice consists of more effective relationships between the professional and the user, one of which is welcoming[5].

In this scenario, it is important to understand that disability is not an individual problem but a social issue, which gives responsibility for bodily limitations to society's inabilities to adapt to heterogeneity[28]. Still, the lack of resources to access public health institutions reveals the neglect of public power. Despite the Brazilian legislation addressing accessibility issues, the reality is different, it still faces the lack of infrastructure, the absence of material goods and transport, conditions that hinder the care of people with disabilities. It is necessary to carry out new studies to better understand the experience of people with disabilities[25].

Barriers to understanding disability

There are numerous terms used to define disability, such as disability, deformity, or malformation, which determines the complexity in understanding this concept. In principle, deficiency presumes alterations or modifications that result in limitations in relation to being and the means of interaction. The often misconception is disagreement about the changes and limitations that represent the disability[29].

The different understandings of these limitations are because some people do not experience disability, as they do not allow this to be the main determinant of their existence, thus preventing disability from becoming an obstacle. In this understanding, disability is not just a consequence of disabilities, but a social environment unfavorable to heterogeneity. Thus, it is understood that the problem is not in the person or his disability, but that the disability takes on a social dimension that leads the person to exclusion[30,31].

Thus, one of the main objectives of primary care is to attribute social visibility to the construction of inclusion, minimizing prejudice, guaranteeing rights, establishing support networks, creating opportunities for socialization and, thus, providing improved access to health services[32]. However, this purpose is a challenge, in view of the fragmentation of care and the lack of integration between the multidisciplinary team, resulting from public policy failures, together with the scarcity of referral and counter-referral services. Consequently, the internal vulnerability of primary care results in uncooperative and non-collective work[33], which is counterproductive to that advocated by the National Primary Care Policy (PNAB)[27,34].

The PNAB assigns exclusive functions to the primary care health team, with the promotion, prevention of health problems, diagnosis, treatment, and rehabilitation of the health of users and registered families relevant to nurses[34]. In this logic, the nurse is the one who ensures the greatest relationship with users, in view of the great closeness to the clientele, and home care greatly collaborates to reduce disabilities, as occurs with people with chronic diseases who experience singular therapies[35]. Fragmented care has repercussions in numerous representations, both for people who experience disability and for professionals who understand the phenomenon of disability / rehabilitation in their own way of acting[32].

For more inclusive and integrated care, there is a need for specific and specialized nursing care, which values human beings in their uniqueness and multidimensionality and is able to articulate with different professionals in a perspective of transdisciplinarity, including different levels of health care, actions and care[36].

The role of nurses as responsible for health promotion and prevention is linked to qualification programs so that they can develop plans and assistance projects in line with the demands of people with disabilities[30,31].

That said, the nursing professional's difficulty in developing care actions with people with disabilities is understood. This difficulty is due to the lack of understanding about the deficiency and the limitation of knowledge in relation to accessibility since it has only valued architectural barriers and not geographical and attitudinal barriers. Thus, the databases, virtual libraries and databases consulted with the adopted descriptors may represent one of the limitations of this study. Research that portrays experiences that may contribute to more inclusive nursing care in Primary Health Care is suggested, the inclusion of other languages in undergraduate nursing courses and continuing education in service with an approach to the subject in question.

Conclusion

It is concluded that the nurse's difficulty in developing care actions with people with disabilities, in view of the lack of understanding about the disability, the lack of mastery in other languages and the limitation of knowledge regarding accessibility. Therefore, they have limitations in the quality of care leading to fragmentation of care, as they consider that these people should be assisted by specialized care. These weaknesses demonstrate that the performance of nursing can better align with the principles of SUS and the Statute of the Person with Disabilities, since the nurse's duties include comprehensive care.

Thus, inclusive care contributes so that the person with disabilities does not become imperceptible from the point of view of the health service, which contributes to low self-esteem, prejudices, and constraints.

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