



REVIEW / THEMATIC ISSUE

Nursing care for children with special health care needs in primary care

Assistência de enfermagem à criança com necessidades especiais de saúde na atenção primária
Atención de enfermería al niño con necesidades especiales de atención en salud en la atención primaria

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ABSTRACT

Objective: To analyze, based on scientific evidence, nursing care for children with special health care needs in Primary Health Care. **Methods:** Integrative literature review, with search and selection in MEDLINE databases via PubMed®, LILACS, Embase, SCOPUS and in the Scielo electronic library. Ten primary studies were included, available in full, published between 2011 and 2021, in English, Portuguese and Spanish. **Results:** Despite the great need for technical knowledge in assisting CSHCN, it is evident the need for these children and their families to be attended in full, and not just with biomedical approaches that limit nursing care in terms of identifying aspects related to the clinical picture of these children. It was also evidenced that nurses, for the most part, do not feel prepared to provide adequate care due to the complexity of the health conditions, the deficiency in professional training or the lack of periodic and specific training after graduation. **Conclusion:** Nursing care in the care for CSHCN happens in a fragmented way and with actions based on the biomedical model. The findings showed little access and inclusion, in addition to a shortage in the provision of training for nurses as a frequent problem in primary care.

Descriptors: Primary Health Care. Chronic Disease. Child Health. Pediatric Nursing. Disabled Children.

RESUMO

Objetivo: Analisar, nas evidências científicas, a assistência de enfermagem às crianças com necessidades especiais de saúde na Atenção Primária à Saúde. **Métodos:** Revisão integrativa da literatura, com busca e seleção nas bases de dados MEDLINE via PubMed®, LILACS, Embase, SCOPUS e na biblioteca eletrônica Scielo. Foram incluídos dez estudos primários, disponíveis na íntegra, publicados entre 2011 e 2021, em inglês, português e espanhol. **Resultados:** Apesar da grande necessidade de conhecimento técnico na assistência às CRIANES, é evidente a necessidade de essas crianças e suas famílias serem atendidas na integralidade, e não apenas com abordagens de caráter biomédico que limitam a assistência de enfermagem quanto à identificação de aspectos relacionados ao quadro clínico dessas crianças. Evidenciou-se ainda que os enfermeiros, em sua maioria, não se sentem preparados para prestar assistência adequada devido à complexidade das condições de saúde, à deficiência na formação profissional ou pela ausência de capacitações periódicas e específicas após se formarem. **Conclusão:** A assistência de enfermagem no cuidado às CRIANES acontece de forma fragmentada e com ações pautadas no modelo biomédico. Os achados mostraram pouco acesso e inclusão, além de escassez na oferta de capacitação de enfermeiros como um problema frequente na atenção primária.

Descritores: Atenção Primária à Saúde. Doença Crônica. Saúde da Criança. Enfermagem Pediátrica. Crianças com Deficiência.

RESUMÉN

Objetivo: Analizar, con base en evidencias científicas, la atención de enfermería al niño con necesidades especiales de atención en salud en la Atención Primaria de Salud. **Método:** Revisión integrativa de la literatura, con búsqueda y selección en bases de datos MEDLINE vía PubMed®, LILACS, Embase, SCOPUS y en la biblioteca electrónica Scielo. Se incluyeron diez estudios primarios, disponibles en su totalidad, publicados entre 2011 y 2021, en inglés, portugués y español. **Resultados:** A pesar de la gran necesidad de conocimientos técnicos en la atención a los NANEAS, se evidencia la necesidad de que estos niños y familiares sean atendidos integralmente, no solo con enfoques biomédicos que limitan el cuidado de enfermería con relación al cuadro clínico de estos niños. Los enfermeros, en su mayoría, también no se sienten preparados para brindar un cuidado adecuado debido a la complejidad de las condiciones de salud, deficiencia en la formación profesional o falta de capacitación periódica y específica después de la graduación. **Conclusión:** El cuidado de enfermería a los NANEAS es fragmentado y con acciones pautadas en el modelo biomédico. Los hallazgos mostraron poco acceso e inclusión, además de escasez en la capacitación para enfermeros como un problema frecuente en la atención primaria.

Descriptores: Atención Primaria de Salud. Enfermedad Crónica. Salud Infantil. Enfermería Pediátrica. Niños con Discapacidad.

INTRODUCTION

Children with a chronic or disabling disease are included in the group of Children with Special Health Care Needs (CSHCN), which is the name used in Brazil to define a group of clinically fragile children, with greater possibility of exposure to individual, programmatic and social vulnerabilities, whose health problems manifest themselves over time with increasing levels of functional limitations, comorbidities, complexity and the need for specific health services.⁽¹⁻³⁾

Epidemiological data indicate that 10% of children are born with some type of disability (physical, mental, hearing, intellectual or multiple), requiring care that meets their specificities - of this percentage, 3% need rehabilitation in health services.⁽²⁾ CSHCN care demands vary as follows: technological demands (need to use certain technologies); modified usual care (need for adaptations to be made to perform daily tasks); mixed care demands (with two or more interconnected care) and medicative (drug-dependent) care demands; and clinically complex care (a combination of all the demands above, including the handling of life support technologies).⁽³⁻⁵⁾

Given the complexity and uniqueness of the care for CSHCN, Primary Health Care (PHC) and, more specifically, the Family Health Strategy (FHS) teams, are the main gateway to the health system. Thus, the actions and strategies developed in PHC aim to facilitate access and ensure that the therapeutic itinerary of these children takes place according to their needs, in addition to those of their families.⁽²⁾

Faced with this scenario, the nursing team, specifically the nurse, as the leader of the nursing team, has an active role in the care for CSHCN, occupying the role of management of Basic Health Units (BHU) and bond formation with the community, with access and resolution.⁽⁶⁻⁷⁾ However, studies have revealed that the attention given by FHS teams to CSHCN is fragile, disjointed and discontinuous, resulting in fragmentation of care, which may be related to the inexperience of professionals when attending to the needs of this population.^(1-2,8)

Additionally, it is understood that nursing care for CSHCN is a challenge, especially for nursing professionals who are faced with a group of children with a morbidity profile and little known needs.⁽⁹⁾ It is expected that this study can point out elements and information in the scientific literature, make known the existing gaps and collaborate with research for the advancement of science. It is also expected to collaborate with the improvement of nursing care for children with special health care needs attended by PHC, as well as to contribute to scientific and social knowledge, since it will be able to expand the knowledge base and understanding of the topic addressed.

In view of the above, this study aims to analyze scientific evidence on nursing care for children with special needs in primary health care.

METHODS

This is an integrative literature review, conducted through the following investigation steps: elaboration of the research question, literature search and sampling, data extraction, critical evaluation of the included studies, analysis, synthesis of results and presentation of the review.⁽¹⁰⁾

The formulation of the question was structured in the acronym PICo, defining itself as P (Population): children with disabilities; I (Phenomenon of Interest): nursing care; and Co (Context): primary health care.⁽¹¹⁾ Thus, this investigation was conducted by the following question: What evidence is available in the literature on nursing care for children with special needs in the context of primary care?

The search and selection took place between the months of September and October 2021, independently by two reviewers, after electronic consultation on the electronic databases: Medical Literature Analysis and Retrieval System Online (MEDLINE via PubMed®), Latin American and Caribbean Health Sciences Literature (LILACS), EMBASE, SCOPUS and, the Scientific Electronic Library Online (SCIELO). Also, a search for cross-references was carried out, in order to retrieve additional evidence. In this review, resources were not used to search for gray literature.

The controlled and uncontrolled descriptors used to operationalize the search were applied according to the specifics of each database and obtained after consulting the Descriptors in Health Sciences (DeCS) and Medical Subjects Headings (MeSH) vocabularies. The search terms were combined using the Boolean operators “AND” and “OR” (Disabled Children OR Disabled Child OR Children with Disabilities OR Children with Disability OR Handicapped Child AND Primary Health Care OR Primary Healthcare OR Primary Care AND Nursing Care OR Nursing Care Management). **Chart 1** presents the search strategy generated in the consulted databases.

Inclusion criteria were articles published in the last ten years (2011 to 2021), available online and in full version, with free access, in Portuguese, English and Spanish and that addressed nursing care for children with disabilities. Articles that did not comply with the purpose of the study, duplicated and incomplete texts, book chapters, reports, news, theses and dissertations, letters to the editor, literature reviews and opinion articles were excluded.

After the search, the procedures for reading titles and abstracts were followed to identify whether the retrieved articles had potential for inclusion. Disagreements were managed by a third reviewer with clinical and methodological experience. Results management was performed by the ZOTERO software, aiming to identify and exclude duplicates, as well as gather and organize the identified publications.

Chart 1. Search strategy generated in the consulted databases. Picos, Piauí, Brazil, 2021.

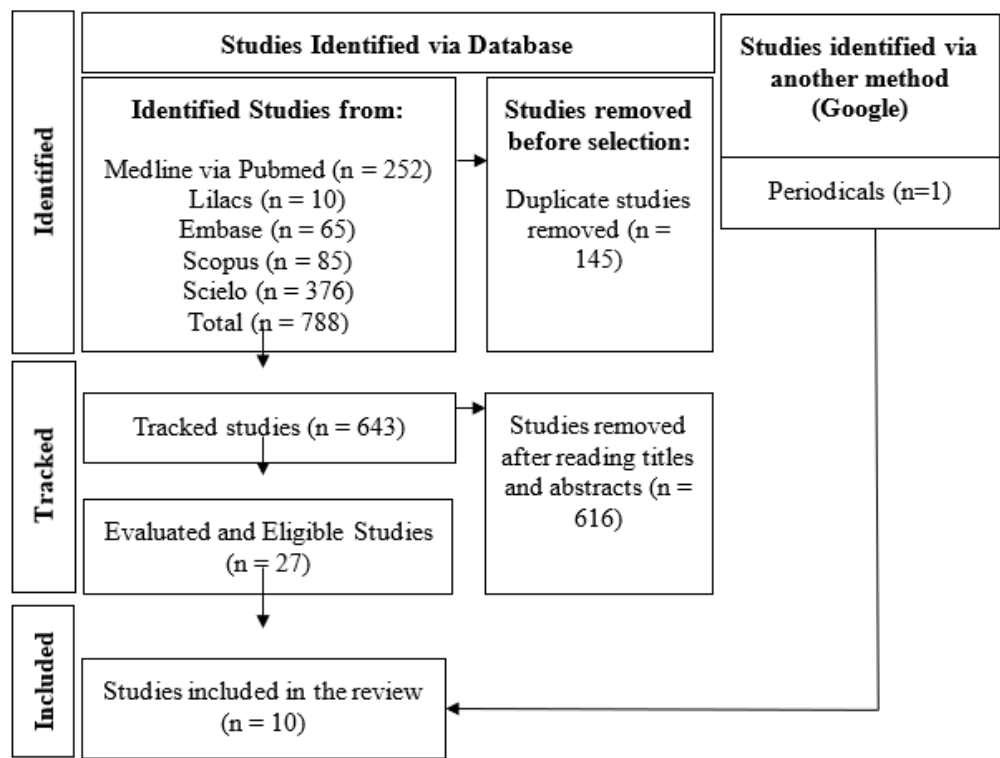
Databases	Search strategy	Number of articles
Medline via PubMed	((("disabled children"[MeSH Terms] OR ("disabled"[All Fields] AND "children"[All Fields]) OR "disabled children"[All Fields] OR ("disabled"[All Fields] AND "child"[All Fields]) OR "disabled child"[All Fields] OR ("disabled children"[MeSH Terms] OR ("disabled"[All Fields] AND "children"[All Fields]) OR "disabled children"[All Fields] OR ("children"[All Fields] AND "disabilities"[All Fields]) OR "children with disabilities"[All Fields]) OR ("disabled children"[MeSH Terms] OR ("disabled"[All Fields] AND "children"[All Fields]) OR "disabled children"[All Fields] OR ("children"[All Fields] AND "disability"[All Fields]) OR "children with disability"[All Fields])) AND ("primary health care"[MeSH Terms] OR ("primary"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "primary health care"[All Fields] OR ("primary health care"[MeSH Terms] OR ("primary"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "primary health care"[All Fields] OR ("primary health care"[All Fields] AND "healthcare"[All Fields]) OR "primary healthcare"[All Fields] OR ("primary health care"[MeSH Terms] OR ("primary"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "primary health care"[All Fields] OR ("primary"[All Fields] AND "care"[All Fields]) OR "primary care"[All Fields])) AND ("nursing"[MeSH Subheading] OR "nursing"[All Fields] OR ("nursing"[All Fields] AND "care"[All Fields]) OR "nursing care"[All Fields] OR "nursing care"[MeSH Terms] OR ("nursing"[All Fields] AND "care"[All Fields]) OR "nursing care"[MeSH Terms] OR ("nursing"[All Fields] AND "care"[All Fields]) OR "nursing care"[All Fields] OR ("nursing"[All Fields] AND "care"[All Fields] AND "management"[All Fields]) OR "nursing care management"[All Fields])) AND (y_10[Filter])	252
Lilacs	crianças com deficiência AND atenção primária à saúde AND assistência de enfermagem OR cuidado de enfermagem AND (db:("LILACS")) AND (year_cluster:[2011 TO 2021])	10
Embase	((('disabled'/exp OR disabled) AND ('children'/exp OR children) OR 'disabled'/exp OR disabled) AND ('child'/exp OR child) AND primary AND ('care'/exp OR care) AND ('nursing'/exp OR nursing) AND [2011-2021]/py	65
Scopus	(ALL (disabled AND child) OR TITLE-ABS-KEY (disabled AND children) AND TITLE-ABS-KEY (primary AND health AND care) AND TITLE-ABS-KEY (nursing AND care)) AND (LIMIT-TO (PUBYEAR , 2022) OR LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013)))	85
Scielo	(((((Disabled Child) OR (Handicapped Children)) OR (Disabled Children)) AND (Primary health care)) OR (Primary Care)) AND (Nursing Care) Filtros selecionados: Ano de Publicação: 2011, 2012, 2013, 2014, 2015, 2016, 2017, 2018, 2019, 2020 e 2021.	376
TOTAL	788	

Source: Authors (2022).

A total 788 productions were found. After applying the eligibility criteria, 10 primary studies made up the sample. The route taken for identification, selection, eligibility, inclusion and sampling followed the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA),⁽¹²⁾ as shown in **Figure 1**.
For data analysis and extraction, an instrument was used according to the variables of interest defined for this study, prioritizing referential aspects (author, year of publication), methodological structure (study design, location/sample, and objective) and main results and conclusions.

The analysis of the results was carried out in a descriptive way, in which the synthesis of the evidence included in the review was presented, as well as the comparisons between the data identified through thematic categories. As it did not involve human beings, this study was not submitted for approval by the Research Ethics Committee. However, ethical principles were maintained, respecting the authors' copyright, by citing each one of them.

Figure 1. PRISMA Flowchart. Picos, Piauí, Brazil, 2021.



Source: Authors (2022).

RESULTS

The study sample consisted of a total of 788 articles; of these, 145 were removed for being duplicates; 616 were excluded after reading titles and abstracts; 18 were excluded for not answering the research question. It is noteworthy that only nine met the inclusion criteria, and one was added based on a search carried out on the Google platform,

totaling 10 studies included in this review, as presented in the PRISMA flowchart (Figure 1).

Chart 2 presents the distribution and synthesis of included studies according to authors, year of publication, study design, location/sample, objective and outcome.

Chart 2. Synthesis of selected studies, related to authorship, year, design, location, sample, objective and outcome. Picos, Piauí, Brazil, 2021.

Authors (year)	Study design	Location/ sample	Objective	Outcome
Guadarrama-Celaya <i>et al.</i> (2012) ⁽¹³⁾	Observational and cross-sectional study.	Mexico and Cuba / 400 children aged 1 to 60 months.	To assess the prevalence of deviations from normal neurodevelopment between Mexican communities and a Cuban community, in addition to verifying the application of Neuropediatric Development (NPED) by the nursing team and the feasibility of introducing this tool in community health centers.	The prevalence of deviations from normal neurodevelopment was very similar between the two countries, and the NPED system fulfills the necessary requirements for mass screening to be applied by the nursing staff at a primary care level.
Kelly <i>et al.</i> (2017) ⁽¹⁴⁾	Exploratory study, qualitative approach.	United States / 399 active members of the National Association of Pediatric Nurse Practitioners (NAPNAP).	To assess the current knowledge of these nurses about the neurodevelopment of children born prematurely.	The research findings imply the need to increase the level of knowledge about neurodevelopmental outcomes of children born prematurely in primary and specialist pediatric health care providers and early childhood educators.

Duarte <i>et al.</i> (2015) ⁽¹⁵⁾	Descriptive-exploratory study, with a qualitative approach, supported by the methodological theoretical framework of the Marxist dialectic.	Belo Horizonte, MG / Nurses, nursing technicians and nursing assistants, working in 16 basic health units.	To analyze the care model that guides the care of children with a chronic condition in primary health care.	There were challenges for the construction of a model that incorporates care for children with chronic conditions in primary health care in order to consider their uniqueness and health needs.
Neves <i>et al.</i> (2019) ⁽⁸⁾	Qualitative research of the descriptive-exploratory type characterized as a bicentric study.	A municipality in the state of São Paulo and a municipality in Rio Grande do Sul / 19 family caregivers.	To know how children with special health needs access the health care network.	Difficulties in care, including nursing care, for children with special needs were pointed out, such as the delay in the process of defining the child's diagnosis and referral to the specialist.
Rosário <i>et al.</i> (2013) ⁽¹⁶⁾	Qualitative study	Mossoró, RN, Brazil / 13 professionals from the Family Health Strategy.	Understand how is the access of children with disabilities to primary health care from the point of view of professionals in the Family Health Strategy.	The access of children with disabilities to primary care health services is difficult due to attitudinal and structural barriers.
Whiting <i>et al.</i> (2018) ⁽¹⁷⁾	Exploratory, qualitative study.	England, Wales and Scotland / WellChild nurses and parents of children with disabilities	Collect data on the experience of parents of children with special needs.	With the support given to parents by the WCNs, it was possible to improve the provision of community nursing care for children, as well as the acquisition of decision-making skills and algorithms that enhance their ability to solve clinical and non-clinical problems throughout the day.
Belmiro <i>et al.</i> (2017) ⁽¹⁾	Descriptive study, with a qualitative approach.	Mossoró (RN), Brazil/ Health professionals from two FHS teams working in PHC	To present the performance of the FHS nursing team in assisting children with special needs.	Nursing professionals did not have adequate preparation in the comprehensive care of children with disabilities, so they do not provide appropriate assistance to this group.
Pérez-Guerrero <i>et al.</i> (2020) ⁽⁶⁾	Qualitative and descriptive study	Province of Camagüey, Cuba/ 226 graduates Doctors in Nursing.	Promote new Nursing practices based on continuing education to improve the preparation of Nursing professionals who work in primary health care in the area of child disability.	Disability is a health problem because of its negative impact on the child, family and community. Nurses are a key element in comprehensive community care for this problem.
Lino <i>et al.</i> (2020) ⁽²⁾	Qualitative study, based on the philosophical framework of Patient and Family Centered Care.	Six health districts of a capital in the Brazilian Midwest / 41 health professionals who worked in the FHS teams, linked to the basic units that had children with disabilities residing in their area of coverage.	Know the care actions performed by Primary Care professionals to families of children with disabilities.	The 13 nurses participating in the study, in addition to other professionals, such as community health agents, nursing technicians and doctors, need specific training so that the assistance provided to families of children with disabilities is focused on comprehensive care and on the needs of the child and their family. In this way, they should recognize their potential, and the importance of autonomy and participation in care.

Favaro LC <i>et al.</i> (2020) ⁽⁷⁾	Descriptive, exploratory study with a qualitative approach.	Conducted with 14 nurses from PHC, who work in the FHS in Maringá-PR.	To apprehend how the nurses of the Family Health Strategy perceive themselves in relation to the knowledge and preparation to assist children with special health needs and their families and how they assess their access to health services.	The lack of a specific protocol and the deficiency in the establishment of a network that prioritizes continuity, comprehensiveness and quality of care restrict and hinder access to specific exams, consultations with specialists, in addition to adequate follow-up in primary care.
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Source: Authors (2022).

Most articles were extracted from the LILACS database. The country with the highest number of studies on the subject was Brazil, with six studies (60%). Regarding languages, six studies (60%) were published in Portuguese, two (20%) in English and two (20%) in Spanish. Regarding the methodological nature, nine articles (90%) are qualitative and 10% are quantitative. As for the design, most (90%) were descriptive-exploratory studies, with a low level of evidence.

The studies evaluated showed that despite the great need for technical knowledge in nursing care for CSHCN, the need for these children and their families to be attended as a whole is evident, with a focus on integrality, and not just with biomedical approaches that limit nursing care to identify aspects related to the child’s clinical condition.

The evaluated outcomes showed that there are many gaps in the care of CSHCN, showing that most nurses do not feel prepared to provide adequate assistance to CSHCN and their families, either due to the complexity of health conditions, deficiency in professional training or lack of periodic and specific training after graduation.

DISCUSSION

The grouping of coincident themes from the selected articles enabled the construction of three thematic categories:

Inclusion and accessibility of children with disabilities in PHC

Three studies were grouped in this category, emphasizing the importance of inclusion and access as an essential element to promote care for CSHCN.^(1-2,16)

In general, CSHCN require longer hospital stays and frequent readmissions, often accompanied by a difficult prognosis. Consequently, the right of access to health services is paramount, at all levels of complexity.⁽²⁾ In this way, accessibility permeates the availability of health services and access by users to inclusive services, confirming the importance of guaranteeing rights to people with disabilities, such as: health, safety, leisure, education and work.⁽¹⁶⁾

However, there are barriers to access in PHC that limit the guarantee of equitable, egalitarian and universal care, as recommended by the Unified Health System (UHS). One of these barriers was mentioned in a study⁽¹⁶⁾ which identified problems related to the infrastructure of health units regarding

exclusive parking spaces for people with disabilities. In addition, the absence of access ramps for overcoming thresholds, physical obstacles and unadapted bathrooms was observed.

In addition, there are other obstacles that make it difficult for CSHCN to access PHC, as it was possible to observe in a study carried out at the FHS in Mossoró/RN, in which CSHCN experienced difficulties in accessing the health service, due to a high demand for assistance and the lack of adequate transport for their locomotion to the PHC, as well as for the commute of health professionals for home care.⁽¹⁾

A study carried out with PHC health professionals revealed little integration between health services in the care of CSHCN and their families, highlighting the absence of a guiding flow in institutional policies, most of which belong to the biomedical model, making inclusion difficult.⁽²⁾

The discussion of these elements transcends the simple presence/absence of obstacles to the use of health services. In this context, the difficulty of inclusion and accessibility requires greater sensitivity and carrying out actions together with municipal, state and federal managers. In the case of a CSHCN, it is not enough to have opportunities when there are no conditions to take advantage of them, compared to a child who does not have a disability. Thus, the principle of equity, the possibility of unequally serving those who are unequal, would be a way to benefit people with disabilities so that they have equal opportunities, prioritizing those who most need attention. For that, it is necessary to transform the subjects and collectivities in real life situations, prioritizing training and professional performance. The change in this reality occurs with the appropriation of knowledge. When talking about knowledge, one does not talk about receiving information, but about raising awareness to realize the need to discover new strategies of action.^(16,18)

A Brazilian study points out that it is common for families of CSHCN to resort to the judicial system to guarantee the minimum necessary care at home, which is not always met.⁽⁴⁾ Generally, these children are better welcomed by large referral hospitals for their continued treatment care than in the health services available in their territory.⁽⁸⁾ Furthermore, it is noteworthy that the care to be provided to CSHCN and family, in order to be considered integral, also needs to visualize the family in its singularity and contextualized in an environment, with beliefs, cultures, and peculiarities of their own.⁽¹⁹⁾

Nursing care for children with special needs in PHC

In this category, five studies were identified that highlighted the importance of nursing care for CSHCN in PHC.^(6,8,14,16-17)

In the studies analyzed, it was found that the focus of nursing care for CSHCN continues to be the pathology, leaving the family in the background, without clear information about the child's diagnosis, and on several occasions, without participating in decision-making and care. It was also evidenced that nurses, for the most part, do not feel prepared to provide adequate care to CSHCN and their families, either due to the complexity of health conditions, deficiency in professional training or lack of periodic and specific training.

The articulation and integration of care for CSHCN is considered important, highlighting the role of nurses in the implementation of actions, according to the attributes of PHC.^(8,16) Training carried out with the objective of offering new nursing practices for integral care to child disability allowed the increase of skills for prevention, early detection and comprehensive care of the disability in patients under 18 years of age. This initiative highlighted the importance of continuing education for nurses in the incorporation of nursing skills and attitudes.⁽⁶⁾

In countries such as England, Scotland, Wales and Northern Ireland, the charity WellChild has worked to improve the provision of community nursing care for children. Among the actions carried out by WellChild, support for CSHCN stands out, especially during “off-work hours”, as it provides services such as counseling and family support. In addition, a variety of decision-making skills and algorithms were made available which increased the ability to solve clinical and non-clinical problems throughout the day.⁽¹⁷⁾

In a study carried out with pediatric nurses who are members of the National Association of Pediatric Nurse Practitioners, a 33-item Premature Birth Knowledge Scale (PB-KS) was used to assess understanding of current neurodevelopmental outcomes in children born prematurely. The mean PB-KS score in the PNP sample was 17.8 (possible score = 0-33), with an average accuracy of 53.9%. Higher scores on the PB-KS were correlated with higher perceived level of preparedness to care for children born prematurely.⁽¹⁴⁾

A study⁽⁸⁾ highlighted the importance of the nurse as a mediator between users and the health team, since nursing has skills to coordinate care. Thus, because the professional nurse is in closer contact with the people of the territory, it is their responsibility to create educational works with the community of their assigned area.⁽⁶⁾ The need to organize the services of PHC is essential, in order to promote effective care for CSHCN, therefore, nursing care needs to be strengthened.⁽⁸⁾

In terms of training, it is believed that the process of continuing education of professionals in the health team can contribute to professional training with the possibility of establishing the Health Care Network (HCN), in a multi-professional and integral way, for CSHCN. This can impact on the reduction of new hospitalizations, improving the quality of life of these children and their families.⁽²⁰⁾ It is believed that the breadth and feasibility of access and follow-

Nursing care for children with special health care needs.. up in PHC, made possible by professionals, can impact on the reduction of morbidity and mortality and the quality of life of these children and their families.

Nursing challenges in assisting children with special needs

In this category, the main challenges facing assistance to CSHCN were described, including the main limitations in the context of nursing care.^(1-2,7-8,13-17)

Worldwide, there is a growing population of children with complex health needs and disabilities who are cared for at home by their parents, 24 hours a day, seven days a week, causing their guardians to bare greater responsibilities regarding care and attention.⁽¹⁷⁾ Despite this, child health care is in the process of being built, along with health care in general, in a movement of paradigmatic change from the model centered on pathology and on the child to a model of building networks, in favor of family inclusion and comprehensive care.⁽¹⁵⁾

Among the challenges of nursing in assisting children with disabilities, attitudinal, geographic, behavioral, architectural, financial barriers, among others, were identified, resulting in stigma and segregation. Such challenges can be justified due to the fact that the health system in Brazil presents limitations in the management of financial, personal and material resources, compromising the access of people with disabilities, even though the universalization of health care is constitutionally guaranteed.^(8,16) Another challenge encountered was the absence of a standard instrument or screening process for the identification of CSHCN, causing them to be identified late, impairing the effectiveness of any form of approach and intervention.⁽¹³⁾

A study⁽⁸⁾ also found that CSHCN had difficulty in accessing consultations when the chronic condition worsened, in addition to constant pilgrimages in search of health care, resulting in a context of inequity in access to health services.

There was also an underestimated importance of nursing care in the therapeutic process, since families of CSHCN sought more medical professionals, especially pediatricians, evidencing a biological conception on the part of caregivers.⁽⁸⁾ According to the above, shortage of nurses' knowledge to carry out the necessary referrals to CSHCN was verified. The scarcity of training was highlighted, with the absence of permanent education actions offered by the service.⁽²⁾

Likewise, the lack of permanent education on the issue makes the work of care providers difficult, causing them to not feel prepared by their institutions, seeking for updates on their own.⁽¹⁴⁾

The nursing team needs to be prepared to give support and backing, requiring training of professionals, qualification of communication between health services and the family at different levels of care, in order to articulate all dimensions of care management to children and adolescents in PHC.⁽¹⁶⁾ It is also important for health professionals to carry out articulated actions through social media and that are centered on the child and their family, as this can contribute to the reorganization of the

Other studies refer to the difficulty in scheduling appointments, lack of transport to carry out appointments and home visits, often requiring the professional to use their own vehicle to carry out the scheduled activities.^(8,16) Thus, the failure to carry out visits to these children by the FHS team reveals the non-compliance with *longitudinality*, one of the attributes of PHC, leaving the responsibility for specialized services and emergency rooms.⁽⁸⁾

Also in this sense, in a study carried out at the FHS in Maringá-PR, the nurses of the unit reported feeling unqualified to care for CSHCN, due to the variety of pathologies, chronic conditions and the difficulty in handling devices such as gastrostomy, tracheostomy, among others, thus generating fear and insecurity in nurses during consultations and even when talking to parents.⁽⁷⁾

Another obstacle encountered was the lack of specific care for children with disabilities, since they have a differentiated demand for care. A study⁽¹⁾ showed that nurses provided care to CSHCN according to the health problems and needs common to all children, without considering, in this way, the peculiarities of CSHCN.

In view of this, the need for measures to improve care for CSHCN is perceptible, highlighting the relevance of training, continuing education for nursing professionals and valuing multidisciplinary care in order to ensure safe and effective care.^(1,7) It is also relevant that nursing professionals provide the family caregivers of CSHCN with moments of listening, recognizing, in the subjectivity of care developed by the family member, spaces for exchanging knowledge and autonomy, so that these caregivers can empower themselves to perform the care demanded by CSHCN in the home space.

This study presented as limitations the scarcity of articles developed in the PHC scenario, with most studies being developed at the hospital level, as well as the predominance of studies with low strength of evidence, for not allowing to establish cause and effect relationships.

The results of the present study can serve as subsidies for the implementation of actions aimed at improving care for CSHCN and their families.

CONCLUSION

In this review, it was identified that nursing care in the care of CSHCN happens in a fragmented way and with actions based on the biomedical model. The results found showed little access, inclusion and scarcity in the offer of training for nurses, constituting a frequent problem in PHC.

It is recognized the role of managers in improving care for CSHCN and the development of other studies on the subject, especially those that focus on articulation, and shared and multi-professional responsibility in the interface of health work in primary care. It is necessary to advance in the organization of care for CSHCN in PHC, with actions that include the specificity of this population group in an offer of care that is more coherent with their specificities.

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The importance of training and qualifying nurses is highlighted so that they are able to carry out their praxis based on respect for the autonomy and citizenship of CSHCN. Health needs are special and specific and require a better organization of the child's health care network.

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