









NURSE'S PERCEPTION ON ASSISTANCE TO CHILDREN WITH SPECIAL HEALTH NEEDS IN PRIMARY CARE

PERCEPÇÃO DO ENFERMEIRO SOBRE ASSISTÊNCIA ÀS CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE NA ATENÇÃO PRIMÁRIA

PERCEPCIÓN DEL ENFERMERO SOBRE LA ASISTENCIA SANITARIA DE NIÑOS CON NECESIDADES ESPECIALES DE SALUD EN ATENCIÓN PRIMARIA

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ABSTRACT

Objective: to learn how nurses from the Family Health Strategy perceive themselves in relation to knowledge and preparation to assist children with special health needs and their families and how they assess their access to health services. **Methods:** descriptive, exploratory study with a qualitative approach, carried out in primary health care. Data were collected through semi-structured interviews with 14 nurses from the Family Health Strategy teams. The interviews were transcribed in full and then submitted to content analysis, thematic modality. **Results:** two categories emerged from the analysis (unpreparedness for assistance and its implications and access to health services in the care network for children with special health needs), which show that nurses, for the most part, do not feel qualified to offer quality assistance; assess the access of these children and their families to health services as difficult, due to the multiplicity of conditions presented by them. **Conclusion:** the lack of a specific protocol and the deficiency in the establishment of a network that prioritizes continuity, integrality and quality of care restrict and hinder access to specific exams, consultations with specialists, in addition to adequate follow-up in primary care.

Keywords: Primary Health Care; Health Services Accessibility; Child Health; Chronic Disease.

RESUMO

Objetivo: apreender como os enfermeiros da Estratégia Saúde da Família se percebem em relação ao conhecimento e preparo para assistir as crianças com necessidades especiais de saúde e suas famílias e como avaliam o acesso delas aos serviços de saúde. **Métodos:** estudo descritivo, exploratório de abordagem qualitativa, realizado na atenção primária à saúde. Os dados foram coletados por meio de entrevista semiestruturada com 14 enfermeiros das equipes da Estratégia Saúde da Família. As entrevistas foram transcritas na íntegra e depois submetidas à análise de conteúdo, modalidade temática. **Resultados:** da análise emergiram duas categorias (despreparo para assistência e suas implicações e acesso aos serviços de saúde da rede de atenção às crianças com necessidades especiais de saúde), as quais mostram que os enfermeiros, em sua maioria, não se sentem capacitados para oferecer assistência de qualidade; avaliam o acesso dessas crianças e suas famílias aos serviços de saúde como dificultado, devido à multiplicidade de condições apresentadas por elas. **Conclusão:** a inexistência de protocolo específico e a deficiência no estabelecimento de uma rede que priorize a continuidade, integralidade e qualidade da assistência restringem e dificultam o acesso a exames específicos, consultas com especialistas, além de acompanhamento adequado na atenção primária.

Palavras-chave: Atenção Primária à Saúde; Acesso aos Serviços de Saúde; Saúde da Criança; Doença Crônica.

RESUMEN

Objetivo: entender cómo los enfermeros de Estrategia de Salud Familiar se perciben en relación con el conocimiento y la preparación para ayudar a niños con necesidades especiales de salud y sus familias y cómo evalúan su acceso a los servicios de salud.

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Métodos: estudio exploratorio descriptivo de enfoque cualitativo, realizado en atención primaria de salud. Los datos fueron recogidos a través de entrevistas semiestructuradas con 14 enfermeros de los equipos de Estrategia de Salud Familiar. Las entrevistas fueron transcritas en su totalidad y luego sometidas a análisis de contenido, modalidad temática. *Resultados:* del análisis surgieron dos categorías (falta de preparación para la asistencia sanitaria y sus implicaciones y acceso a los servicios de salud de la red de atención para niños con necesidades especiales de salud), que muestran que la mayoría de los enfermeros no se sienten calificados para brindar atención de calidad; consideran que el acceso de estos niños y sus familias a los servicios de salud es difícil debido a la multiplicidad de condiciones que presentan. *Conclusión:* la falta de un protocolo específico y la deficiencia en establecer una red que de prioridad a la continuidad, integralidad y calidad de la atención sanitaria restringen y complican el acceso a exámenes específicos, consultas con especialistas, además del seguimiento adecuado en la atención primaria.

Palabras clave: Atención Primaria de Salud; Accesibilidad a los Servicios de Salud; Salud del Niño; Enfermedad Crónica.

INTRODUCTION

The advancement of technology and the evolution of scientific and pharmacological knowledge brought children with complex health conditions, resulting from problems such as prematurity, congenital malformation, chronic diseases and trauma, more life expectancy.¹ This resulted in a group of children dependent on technology and/or health care, referred to in Brazil as children with special health needs (CSHCN).²

CSHCN have limiting or disabling conditions, which can be motor, functional, behavioral, emotional and/or developmental; and chronic dysfunctions, which requires continuous, temporary or permanent care. Thus, in addition to more use of general health services,³ they also depend on different special services, both health and social, which go beyond the services required by children in general.⁴

It is important that professional Nursings are prepared to receive these children, including in primary care context. Thus, the updating of nurses and continuing education must transcend hospital practices and techniques and view the home environment as a rich and precious space for health care.⁵

Care practices with CSHCN have signaled the importance of planning care for this child group, taking into account the complexity they present.⁶ In this context, the Family Health Strategy (FHS) is seen as a possible articulator in the instrumentalization and support of the family unity to face the child's chronic condition, because through territorialisation and other instruments can guarantee access to health, considering their vulnerabilities and needs.⁷ However, a study conducted in Maringá - PR found that children with multiple, complex and

continuous special care needs, in general, have no connection with primary health care (PHC), and when they have it, it is weak/restricted and often used only for the removal of inputs for daily use.⁸

In view of this reality, the following question arose: the fact that the children and their families are not effectively assisted by the FHS is related to the nurse's qualification to assist this group of children? In order to answer this question, the objective of this study was defined: to apprehend how FHS nurses perceive themselves in relation to knowledge and training to assist CSHCN and their families and how they assess their access to health services.

METHODS

This is a descriptive-exploratory study with a qualitative approach, conducted with 14 nurses from primary health care (PHC), more specifically with nurses working in the FHS of Maringá - PR. At the time of the study, the municipality had 32 basic health units (BHU) and 72 FHS teams. The Municipal Health Secretariat authorized the research to be carried out with professionals working in five BHU, all located in the same region of the city, which allocated 20 FHS teams.

The inclusion criterion was the fact that the nurse has been working for more than six months in the same FHS team, an aspect attended by all. In turn, three nurses who were on vacation and two who were on leave were excluded. It should be noted that one nurse did not accept to participate in the study.

To start the research, contact was made with the coordinators of the BHU and nurses of the FHS teams to present the project and request to participate. Data were collected from October 2016 to January 2017, through semi-structured interviews carried out in the work environment, in a reserved room, on a previously scheduled day and time, according to the availability of the nurses.

The interviews, after authorization by the participants, were audio-recorded, lasted an average of 20 minutes and were guided by a script consisting of questions about professional characteristics, with a guiding question - "how is the assistance to children with special health needs and their families in your team?" - and some support questions addressing the knowledge on the topic, the assistance offered in PHC, the access of this population to the health service and the preparation to assist CSHCN.

All interviews were transcribed in full and submitted to content analysis, thematic modality, following the proposed steps: pre-analysis, material exploration and data categorization.⁹ In the **pre-analysis**, the message was organized through the choice and reading in suspension of the acquired

material, based on the established hypotheses and objectives. In the **material exploration** stage, the raw data from the message were encoded. And finally, in the **data treatment and interpretation** stage, the data were classified through the isolation/differentiation of the message elements, with subsequent regrouping by similarities, followed by inference and interpretation.⁹

The project was approved by the Research Ethics Committee with Human Beings, of the *Universidade Estadual de Maringá* (Opinion Report Nr. 1,751,336/2016), according to Resolution Nr. 466/12 of the *Conselho Nacional de Saúde* (BR). All participants signed the Free and Informed Consent Form Informed (ICF) and to guarantee their anonymity, in the presentation of the results the quotes of their speeches were identified by the letter E for nurse and a number indicating the order of the interviews.

RESULTS

The 14 nurses in the study were aged between 31 and 52 years (mean 34.7 years), 12 were female and eight had children. The length of experience in the FHS varied from 10 months to 16 years. The average time of work in the current FHS team was 6.21 years; nine nurses were specialists and four had already worked in the Hospital Pediatrics sector; 10 stated that there were CSHCN in the area covered by their team, but did not know how to quantify the exact number of children. It is noteworthy that only one nurse reported having participated in continuing education addressing the care of these children, which occurred at the time while worked in hospital care. Two categories emerged from the data analysis, described below.

LACK OF QUALIFICATION FOR ASSISTANCE AND ITS IMPLICATIONS

The study nurses reported not feeling qualified to assist CSHCN, as they experience difficulties in handling devices (gastrostomy, tracheostomy, nasoenteral tube, among others) and even to deal with parents. According to their statements, they need training, updates and psychological support:

We have not received any continuing education up to now. No training related to this (E01).

We are not prepared, we have no experience and our health system does not prepare us to work with this audience, so we have difficulties. There is no course, preparation for everyday life, recycling, guidance, nothing!

[...] there is training for everything, except for children with special health needs (E04).

I don't feel prepared neither psychologically nor technically (E06).

There is a lack of training for us to work with mothers or fathers, to be attentive, which is a risk factor, how to encourage it, when something is missing (E10).

There should be training for us, the health team, of simple, everyday things that these children need. Gastrostomy, we know [...] but it needs updating (E14).

Assistance to CSHCN, in the view of the nurse from FHS, is hindered by the multiplicity of diseases and chronic conditions, since each child has specific needs for attention and different demands for care. The existence of so many peculiarities triggers fear and insecurity in serving this people:

Not all of them, we are aware, we do not know the particularity of each disease and each Nursing care (E02).

Ah, it is difficult, knowing how to deal, how to act, many use tubes, a lot of medication (E09).

Training is a way for us to remove stigma, prejudice and fear. As we don't have much practice, we are unsure of how to deal with these children. If you have training, it's easier (E09).

Because if I don't have knowledge, I can't help, I can even hinder (E13).

We need information, we need recycling [...] it's a disease that you don't have much contact with and you show up there, you don't know much about what you do, or what it brings as a result, or what you have what to do (E13).

So [...] I don't feel empowered. At graduation, I had no contact in the community, only in the hospital and everything, but in the community, dealing with them in the community is something else (E01).

In the absence of formal training, some nurses reported that they seek, on their own, the knowledge necessary to assist CSHCN in the best possible way:

I don't feel prepared, but if I have any difficulties, I look for ways to improve; sometimes I will first investigate how to do it, seek help, and then do it (E09).

With many situations I feel prepared, but there is always something new that I will have to seek to learn. I think in this way [...] I don't know everything; I am open to learning. Sometimes I learn from the mother, sometimes with another professional, sometimes with the academia, sometimes looking for my own resources[...] (E03).

However, some nurses stated that they do not understand their real role in caring for these children. In most cases, however, they recognize the importance of interdisciplinary work and the need to seek help:

I often feel devalued in the treatment and monitoring of this child (E03).

Each professional is important in their role, and in the group, we can provide assistance with quality to this child. I work after information and means so that I can contribute as a member of the team and I see myself as an active participant (E03).

I think we would offer the best possible service, but it is a case that I need to see, evaluate, understand? Study the case, discuss with the doctor, with other people and nurses who have more experience with the topic (E12).

The lack of humanization of care was another point addressed:

Professionals need to have more love in their hearts and work, really looking at the patient, because there are people that the prescription is ready before the patient arrives at the office (E04).

I think we need to improve since the awareness process, we must be more aware and our managers in general [...] have a look, a more appropriate policy for these people (E05).

It is not like that you arrived with a special child. There will be a box where you will enter and attend only the child. No, we plan according to the needs of the family (E14).

It was possible to understand with the reports included in this category that nurses who work in primary care, to

properly assist the CSHCN and their families, need to be better equipped - through training and permanent education - in addition to acting in a perspective of valorization multidisciplinary and interdisciplinary work.

ACCESS TO HEALTH SERVICES IN THE CSHCN CARE NETWORK

According to the nurses under study, the lack of knowledge and experience in dealing with the specific health of CSHCN and their families constitutes an obstacle in the care of these children in primary care:

We would be hindering access due to our lack of knowledge and experience with these cases [...]. It would not be easy, because we, as a professional, did not experience any cases, did not receive any training on this, how to approach every child and family, we did not have any training, so I think it would be difficult, it would be tangled in the bureaucracy and I don't know (E01).

One nurse even reported that at the BHU where she works, even healthy children, who do not have special needs, when they have any complications, are not attended:

Usually, as my doctor here [of the FHS team] does not assist children under nine years old, he sends everything to the emergency care unit (ECU) in the north region, refers to the Pediatrician. He looks and says: this is not for me, even children who have no special needs, children in this group that he does not put his hand on (E04).

Closing the service agenda, as a way of organizing the service, also limits the access of CSHCN to this level of assistance, including in cases of complications:

So [...] in fact, we set up the agenda and kind of shortly close the access, to organize our service (E13).

Some nurses, however, mentioned that the access of the CSHCN in the BHU occurs without difficulties or disorders:

In fact, access is normal through the entrance door to the basic health unit (E01).

The access here in the unit I rate as quiet. She comes, the door is opened, talks to me or makes an appointment with the doctor (E03).

In addition to access for routine follow-up, these children need differentiated and priority care in case of complications:

These children are punctual, I cannot treat them the same way that I treat others, because their needs are different (E03).

Follow-up, in turn, must be based on a care plan that considers the child's real needs, which may involve different professionals and medical specialties and also specific materials and equipment:

Sometimes, I run after a special bed, special supplementation, dressing material [...] it's the probe, it's an aspirator [...] that kind of thing that we are always following (E05).

For us to work with these children, we need a service network, it's not just us here. We need support from other services, physiotherapist, occupational therapist, specialist doctors, gastro, neuropediatrician. We provide basic care, follow-up here, but we always must resort to other means, other specialties (E02).

We need multiprofessional care, not only the nurse, we will need a psychologist, a nutritionist, a physiotherapist, a speech therapist, here in this unit, we don't have it (E14).

However, despite recognizing the importance of these children being assisted by different professionals, they report that access to specialties and specific exams is difficult and time-consuming:

It takes a long time for specialized consultations (E08).

Unfortunately, the specialty, in general, is complicated and for children it is the same case (E03).

The specialties [...] it's more complicated. They are referred to a certain specialist who asks for an examination, which is more complex, then it takes time because they have to go through the social worker first because Unified Health System (Sistema Único de Saúde, SUS) does not cover it, so they have to make a special request, sometimes via court. So, there are these [...] specialized exams, I think are more complicated. For those who use SUS (E02).

In the municipality under study, this group of children has consultation/assistance at other levels of care, such as

the outpatient clinic of the University Hospital, the Northern Parana Association of Rehabilitation (*Associação Norte-Paranaense de Reabilitação*, ANPR) and the Parents and Friends of Disabled People Association (*Associação de Pais e Amigos de Excepcionais*, APAE). The professionals consider that children who are taken in by these services together with PHC have their needs fully met:

If you can go to the outpatient clinic of the University Hospital and ANPR, then it is much easier. I have a child who is assisted at the ANPR and in the outpatient clinics, so she is assisted in full (E14).

However, the lack of counter-reference makes it difficult to maintain follow-up in PHC, in addition to the risk of contradictory guidelines and conduct between the different services, which can result in damage to the children's health:

We have the University Hospital, the children are assisted for there also have no return from everything that is happening, often I will make a home visit, the patient had to go to the clinic, and changed a medication, [...] this is missing [...] really have this reference and counter-reference (E14).

Primary care should be the basis of care and service to CSHCN, with a view to expanding the subjects' autonomy, through the expanded clinic, offering solutions to health needs and demands and providing networks for this assistance.

DISCUSSION

According to the nurses under study, the lack of training directly influences the way care is provided, as the feeling of not being technically prepared to perform specific activities in relation to the CSHCN results in insecurity and fear, which makes it difficult to offer adequate follow-up. The assistance to this group of children requires, in addition to an appropriate physical structure, professionals prepared to offer adequate support that meets the biological and psychosocial needs.¹⁰ It is common among CSHCN the need to use technologies for survival. A study that addressed the assistance to CSHCN in eight home care services (HCS) in the state of Paraná found that 91% of them were dependent on some technology, the most frequent being tracheostomy (60%) and gastrostomy (57.1%).¹¹ Therefore, the knowledge and technical preparation for handling these devices and carrying out complete and specific guidelines, as well as training and supervision/support to caregivers, is essential to assist this population. In this sense, the authors emphasized the

need for the elaboration and implementation of protocols, with a view to standardizing Nursing techniques at different levels of care.¹¹ This would allow for more articulation between services, in addition to favoring capacity building and practical training of professionals, enabling safer and more competent performance in these families and, consequently, better assistance to CSHCN.

It should be noted that, despite the great need for technical knowledge in care, an integrative review study on Nursing care and family care for CSHCN reveals the need for these children and their families to be assisted as a whole, and not just with a focus in biomedical care. For this, in addition to having a good bond with these families, nurses need technical skills and more specific theoretical knowledge, so that they can better guide and support them in the performance of daily care.¹² Health care actions do not may be limited to the identification of aspects related to the child's clinical condition. Comprehensive care is needed that addresses the biopsychosocial aspects, not only of the children, but also of their caregivers, providing the experience of significant experiences for the child and his family and maximizing potential, instead of just observing the child condition.¹³

Thus, in the case of CSHCN, it is essential that Nursing develops skills to also take care of their families, understanding their limitations, clarifying doubts, contributing with their knowledge and practices, expanding the possibility of acting in the care process and in decisions related to the same. The bond between professional-child-family helps in rehabilitation, improves care, the provision of care and the quality of care¹⁴ and allows the professional to integrate and at the same time foster the social support network of this family.¹⁵

In this sense, and considering that people with disabilities must have humanized attention and focused on their needs,¹⁶ the National Policy for Humanization in Health, created in 2003, aims to implement the principles of SUS in the daily care and management practices; change the ways of producing health care, aiming at humanized and resolute care through a better bond between professional and user.¹⁷

Considering that CSHCN require comprehensive care and special care, quality assistance, even in adverse situations, is possible if there is interest and willingness on the part of the professional to seek the necessary knowledge. Health professionals, particularly nurses, must be prepared and trained to meet their care demands and the demands for guidance and monitoring of their families.¹²

A study carried out at Columbia (USA) highlights the need for effort, education and training to incorporate initiatives to improve care for CSHCN.¹⁸ Continuing education empowers professionals, even individually, updating and/or remedying knowledge deficits and enabling access to new care technologies. In continuing education, health work is the result

of the interaction of team professionals among themselves and with users. Thus, those involved must problematize reality collectively, in order to understand it and build solutions to the problems that arise. The importance of knowledge is not neglected, but its application is secondary to the process of collective construction in solving problems.¹⁹

The training and continuing education actions are complementary to the training of professionals, enabling them to work in specific scenarios, and have the challenge of stimulating critical awareness, through questions and arguments with which the professional continues to learn, which subsidizes the development and implementation of quality assistance.²⁰

It is important to emphasize that the responsibility for training and keeping professionals updated is not only the institutional management, but mainly the professionals themselves. It is believed that the feeling of devaluation of nurses in the care of this public, as identified in this study, is partly the responsibility of the professional, when knowledge is not sought and there is no share of responsibility in the care of the CSHCN residing in the area of scope of its team, since care is at the heart of Nursing. Therefore, everyone involved in user assistance should be encouraged to participate in planning and carrying out actions, as well as identifying the team's training needs.

The nurse, being the leader of the Nursing team, must be a key part of education in the Nursing team. Furthermore, in most cases, the nurse is responsible for the management of the BHU and for the coordination of the FHS teams, which allows this professional to guarantee the access and the resolution of the users' health demands. However, sometimes, due to the association of administrative and assistance activities, it is unable to properly manage time and meet all the demands of the enrolled population.

It should be noted that the various demands related to rehabilitation and reduction of complications arising from chronic conditions of the CSHCN require that assistance be implemented by a multidisciplinary team.²¹ The exchange of information and experiences between different professionals of the health team contributes to the improvement of assistance provided to these children.

In this way, the multiprofessional work enables the exchange of experiences and knowledge, stimulates changes towards the integrality of the services provided, culminating in the improvement of relationships between the members of the health team, which, in turn, reflects better assistance.²⁰ Thus, when nurses and other team members value multidisciplinary work and recognize the importance of teamwork, overload can be alleviated or even resolved.

Considering the importance of multiprofessional work, in Brazil, in 2008, the Family Health Support Centers (*Núcleos de Apoio à Saúde da Família - NASF*) were established, whose

purpose is to resolve and expand primary health care actions, through the support of a multiprofessional team. They can be integrated by speech therapists, physiotherapists, occupational therapists, nutritionists, psychologists, social workers, physical educators, pharmacists, acupuncturists and homeopathic doctors, among others. The definition of which professionals will integrate the NASF in each municipality depends on the health needs, socioeconomic vulnerabilities and epidemiological profile of the different territories in which the health services are located.²² In the case of CSHCN, due to the numerous limiting and/or disabling conditions that can present, the members of NASFs can contribute a lot to the quality of the assistance provided, in the sense of making it more comprehensive and specific.

The nurses in the study stated that CSHCN' access to the service is sometimes hindered by the way it is organized, which is contradictory, since one of the principles of primary care is universality. This level of assistance, therefore, must guarantee universal and continuous access to quality and effective health services. In addition, it should be the preferred gateway to the health care network, welcoming people and promoting connection and co-responsibility for attention to health needs.⁷

Difficulty in accessing health services is not an exclusive problem in Brazil. In a study carried out in the United States with more than 10 million families of CSHCN, a third of them (35.3%) reported difficulties in obtaining health care.²³ A pilot study conducted in *Curitiba* - PR identified difficulties in access mainly related to barriers in transport and buildings, in addition to the lack of training of professionals in assisting CSHCN, showing that the fundamental rights of children and adolescents with disabilities are not yet fully guaranteed.²⁴ Thus, it is necessary for managers to act to enable the access to universal care, training and qualification of professionals to provide comprehensive care.²⁵

According to the National Policy for Primary Care (*Política Nacional de Atenção Básica* - PNAB), these are common duties for all team members who work at this level of assistance: ensuring health care for the registered population and meeting spontaneous demand. Even in complex cases that require referral to other points of care, monitoring the prescribed therapeutic plan is the responsibility of the primary care team.⁷

For this group of children, coping with chronic disease is a daily battle and requires continuous care, as their health condition can progress in a serious way.²⁶ Given this reality and considering the present complexity, care and care practices for CSHCN need more dedication in planning the actions to be implemented,⁶ at all levels of assistance.

In addition to quality care in PHC, these children need specialized monitoring by different professionals, so that their health needs can be better assisted, thus allowing the maximum

development of their capacities.⁶ Therefore, it is necessary an assistance network consisting of points of care at different levels of assistance and with the work of professionals from different specialties.

It is also emphasized the importance of health professionals to know the daily life of CSHCN and their families, paying attention to the need for them to be accompanied by PHC, in order to minimize readmissions. This monitoring should start at the time of hospital discharge and involve multiprofessional care networks, in order to provide a better quality of life, not only for CSHCN, but also for their family.²⁷ A cohort study carried out with 733 CSHCN in the United States compared the use of health services before and after inclusion in a family-centered care coordination program. The results indicated that the monitoring by a responsible health professional (nurse or social worker) and trained to assist the CSHCN significantly reduced the number of hospitalizations and visits in emergency services, which demonstrates the importance of adequate management of care by a trained person in the reduction of health complications.²⁸

In this sense, Ordinance Nr. 793 of 2012 established the Care Network for People with Disabilities within the scope of the Unified Health System (*Sistema Único de Saúde* - SUS), which advocates the creation, expansion and articulation between the different points of health care in SUS for people with hearing, physical, visual, intellectual and/or ostomy disabilities. According to this Ordinance, people with disabilities must be guaranteed access and quality in services, comprehensive care and multiprofessional assistance, under the interdisciplinary logic, so that there is integration and articulation of rehabilitation services with the primary care network and others points of specialized attention.¹⁶

Difficult access to medical specialties has been one of the main barriers to comprehensive assistance to CSHCN, characterized by the long waiting time for exams and specialized consultations. This can generate, among other consequences, suffering for the child and for the child's family, for not being able to resolve the situation, since the child performance is limited, in addition to the possibility of worsening the clinical condition.

Currently, the lack of specific public policies for this infant group results in a process of judicialization of care, in an attempt to favor minimum conditions of survival for these children.²² However, PHC professionals have difficulty communicating with specialized services, due to the failures in counter-referral, which was also identified in a study conducted in *Belo Horizonte* in home care services in *Paraná*.¹¹ It is worth noting that the current assistance scenario is marked by the fragmentation of services and actions. The lack of interaction between the different levels of care, the different sources of financing, the diversity of professionals involved, and the inequality of resources are some

of the factors that hinder integration in health care and delay the implementation of more effective treatment.

Thus, it becomes necessary to give more visibility to the aspects related to this theme in the scope of primary care - ordering care in the care networks - in order to provide assistance in line with the principles of universality and integrality. And Nursing, under the coordination of the nurse, has a lot to contribute to the recognition, planning and incorporation of effective assistance by health teams, favoring the quality of life of CSHCN and their families.

It was detected as a possible limitation of the study the fact that it was performed only with nurses and only those working in five FHS teams, which does not allow inferences about the assistance to the CSHCN even in the municipality under study. Thus, there is a need for studies with a larger population range, and even with other professionals who are part of the FHS teams and with their own family members, in order to provide a better understanding of how assistance is provided to this population in PHC health services. In any case, the results of the present study can serve as subsidies for the implementation of actions that aim to improve the assistance to CSHCN and their families.

FINAL CONSIDERATIONS

The results made it possible to apprehend that the nurses under study 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 the lack of periodic and specific training. It also allowed to identify that, in the nurses' perception under study, the lack of a specific welcoming policy for CSHCN restricts access to health services, making it difficult to perform specific exams, consultations with specialists, in addition to adequate follow-up in primary care.

These children and their families need differentiated and continuous care, which implies the existence of a care network with more interaction between the different levels and the training of professionals, especially those in primary care, given the proximity to these families, to welcome and meet the demands of daily care and, when necessary, make the necessary referrals.

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