



Challenges of family caregivers of children with special needs of multiple, complex and continuing care at home

Desafios de cuidadores familiares de crianças com necessidades de cuidados múltiplos, complexos e contínuos em domicílio

Desafíos de los cuidadores familiares de niños con necesidades de cuidados múltiples, complejos y continuos en el domicilio

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ABSTRACT

Objective: To describe the challenges of family caregivers of children with special needs of multiple, complex and continuing care at home. **Methods:** Qualitative study based on the theoretical framework of the Patient and Family-Centered Care (PFCC). We interviewed eleven family caregivers from 13 children enrolled in a special school in the Brazilian city of Maringá (PR). The data were subject to content analysis, thematic modality. **Results:** The main challenges identified are the lack of preparation for home care, the difficulty of access and follow-up in Primary Health Care services, and the difficulty of including the child in social interaction. However, caregivers react positively to these adversities. **Conclusions and implications for practice:** The nurses need the necessary training to transcend hospital technical care and to develop a care practice based on family-centered care, considering this as a protagonist, including it in the process for the quality of life of these children.

Keywords: Pediatric Nursing; Child Health; Family Nursing.

RESUMO

Objetivo: Descrever os desafios dos cuidadores familiares de crianças com necessidades especiais de cuidados múltiplos, complexos e contínuos em domicílio. **Método:** Estudo qualitativo fundamentado no referencial teórico do Cuidado Centrado no Paciente e na Família. Entrevistaram-se 11 cuidadores familiares de 13 crianças matriculadas em uma escola especial de Maringá (PR), Brasil, sendo os dados submetidos à análise de conteúdo modalidade temática. **Resultados:** Os principais desafios identificados envolvem despreparo para o cuidado domiciliar, a dificuldade de acesso e acompanhamento nos serviços de Atenção Primária à Saúde e a dificuldade de inclusão da criança no convívio social. Entretanto, os cuidadores reagem positivamente frente a estas adversidades. **Conclusões e implicações para a prática:** Os enfermeiros carecem de formação que lhes permita transcender o cuidado técnico hospitalar e desenvolver uma prática pautada no cuidado centrado na família, considerando esta como protagonista, incluindo-a no processo em prol da qualidade de vida dessas crianças.

Palavras-chave: Enfermagem Pediátrica; Saúde da Criança; Enfermagem Familiar.

RESUMEN

Objetivo: describir los desafíos de los cuidadores familiares de niños con necesidades especiales de cuidados múltiples, complejos y continuos en el domicilio. **Método:** estudio cualitativo fundamentado en el referencial teórico del Cuidado Centrado en el Paciente y en la Familia. Se entrevistó a 11 cuidadores familiares de 13 niños matriculados en una escuela especial del estado de Maringá (PR), Brasil, siendo los datos sometidos al análisis de contenido modalidad temática. **Resultados:** los principales desafíos identificados involucran la falta de preparación para el cuidado domiciliar, la dificultad de acceso y el acompañamiento en los servicios de atención primaria de salud y la dificultad de inclusión del niño en la convivencia social. Sin embargo, los cuidadores reaccionan positivamente frente a esas adversidades. **Conclusiones e implicaciones para la práctica:** los enfermeros carecen de formación que les permita transcender el cuidado técnico hospitalario y deben desarrollar una práctica pautada en el cuidado centrado en la familia, considerando ésta como protagonista, incluida en el proceso en favor de la calidad de vida de esos niños.

Palabras clave: Enfermería Pediátrica; Salud del Niño; Enfermería Familiar.

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INTRODUCTION

With the advancement of life-sustaining technologies, chronic childhood conditions related to the increased survival of preterm infants, congenital malformation, syndromes or life-long interurrences have increased¹. The epidemiological profile of childhood in Brazil suffered changes due to this advance, originating a group of children initially named in the United States as Children With Special Health Care Needs (CSHCN)² and as *Crianças com Necessidades Especiais de Saúde* (CRIANES) in Brazil. Recently, a study that carried out the translation and cross-cultural adaptation of a screening tool for these children in Brazil, updated the translation for *Crianças e Adolescentes que Necessitam de Atenção Especial à Saúde* (CRIANES)³.

The CSHCN demand care of technological development, medicament and/or habitual modifications, being classified as children of mixed care, when they present one or more demands of care - excluding the technological one. Those that present the whole set of demands are classified as clinically complex⁴.

This clientele presents greater limitations for the development of basic daily activities, due to neuropsychomotor impairment, demand management of technological devices and differential access in health services, since it uses them more frequently due to the susceptibility to illness and the development of chronic conditions when compared to children without health impairment⁵. This fact results in family suffering and higher financial expenses for the family and the State⁶.

Although there is no epidemiological data on the number of CSHCN in Brazil, a study carried out in three municipalities (Santa Maria/Rio Grande do Sul State, Ribeirão Preto/São Paulo State and Rio de Janeiro/Rio de Janeiro State) found a prevalence of 25.3% among children under 12 years³. The lack of knowledge about these children's reality of life and their families directly influences health care policies and assistance to them⁷. In addition, there is still no protocol that establishes specific care practices for these children. This makes professionals, as a rule, working together with families without the necessary proximity to the perception of their real needs, besides not actively participating in the organization of care under construction, preventing the promotion of a more adequate and safe assistance in the home scope⁸.

Regarding social interaction, studies carried out in Santa Maria/RS identified the isolation of CSHCN and their families due to fear and insecurity that the child's exposure worsens their health condition^{9,10}. Thus, the lack of access to information and health services makes these families structure their social network of support within the community and their extended family¹¹.

Nonetheless, nurses act as the main mediator in the process of adaptation and qualification of family members for articulation and management of family care with CSHCN and the accomplishment of daily tasks at home, promoting a higher quality care. Health professionals should also consider that family daily life is often altered by the need for (re)organization of care for the child and their demands, and it is fundamental to

involve the family in this process so that it actively participates, demonstrating its facilities and difficulties^(12, 13). For this, the nurse is the professional that has specific skills to enable the family in performing this task - to prepare it to carry out home-based care and to give continuity to the child's therapeutic plan¹⁴.

The family is the main unit of care - essential for proper and continuous treatment of the child - and it can be said that it is the main influencing element in the way care is taken⁸. The need for the family caregiver to develop continuing and complex care to these children at home for their survival is highlighted as an issue of this study.

In view of the above, we ask: What are the challenges faced by family caregivers of children with special needs of multiple, complex and continuing care at home? To answer this question, the objective was to describe the challenges of family caregivers of children with special needs of multiple, complex and continuing care at home.

METHOD

This is a descriptive study of a qualitative approach, which used as a theoretical/philosophical framework of Patient and Family-Centered Care (PFCC) approach, based on the principle of family, considering it as the main unit of care¹⁵. 11 family caregivers of 13 CSHCN were subjects of the study and were selected from data collected in a rehabilitation teaching institution's archive, located in the city of Maringá/PR.

The inclusion criteria for participation in the study were: To be 18 years old and above and to be a family caregiver of CSHCN residents in the municipality where the research was carried out. For the definition of eligibility as CSHCN, it was adopted the prerogative that they contemplate at least three of the four categories of demand that characterize them, demand for development care, drug, technological and customary modified, because the lack of one of these elements would not detract from the degree of clinical fragility and the complexity of the care required by them at home. We should note that all the families included in the study had at least one child with the four demands for care.

Initially, we analyzed all medical records of the children enrolled in the teaching and rehabilitation institution, seeking those that met the criteria for inclusion in the study, thus identifying 68 eligible family caregivers. Of this total, the families that participated in the study (11 family caregivers of 13 children - one twin and two siblings of different ages) were intentionally selected. After that, a home visit was scheduled to collect the data through a semi-structured interview, with the guiding question: "Would you tell me about your family's experience of taking care of (child's name) at home?"

All the interviews were carried out by the first author (master's student in Nursing), from June to September 2015, with an average duration of 40 minutes, recorded by authorization, and later transcribed in full and submitted to the analysis of content thematic modality¹⁶. We applied the criterion of theoretical density of the data was applied for closure of the interviews, considering

the scope of the study objectives¹⁷.

The analysis of the empirical material occurred in three phases, following the proposed in thematic modality¹⁶: a) pre-analysis: Organization of the material in order to prepare it for identification of the central idea; b) exploration of the material: In-depth study of the data, aiming to identify the cores of meaning; c) categorization of data: Regrouping of data with the similarity of their meanings.

At the end of the data analysis, three categories arose. In this article, one of them will be presented: Challenges of family caregivers of children who need multiple, complex and continuing care at home.

Subsequently, we interpreted and discussed the results in light of the central assumptions of the PFCC: Dignity and respect, which establishes the need for the professional to respect the family and incorporate it into the planning for care; information sharing; family participation in care; elaboration and development of public policies in order to meet the needs of the family¹⁵, and in order to value it as a unit of care.

The study was developed in accordance with the ethical precepts disciplined by Resolution 466/2012 of the National Health Council (*Conselho Nacional de Saúde*) and was approved by the Research Ethics Committee under Opinion 083705/2014; CAAE (Certificate of Presentation for Ethical Consideration): 36505814.8.0000.0104. All participants signed the Free and Informed Consent Form in two ways. In order to guarantee anonymity, the excerpts from the interviewees' statements were identified by affixing the interviewee to the child followed by the initial letter of the child's first name and age (Ex: Mother of N, 05 years old).

RESULTS

Challenges of family caregivers of children who need multiple, complex and continuing care at home

The results of the study allowed us to understand the main challenges that marked the experience of families participating in the study when caring for a child who needs multiple, complex and continuing care at home. These families had to reorganize to meet the needs of the child, and the main family caregiver left the job to devote himself exclusively to attending to their care demands. In the midst of this, we verified that the poor infrastructure of houses and the lack of equipment adapted to the specifics of the children made difficult the execution of the home care.

The main challenges that emerged from the analysis of the data, characterizing the subcategories, are: *Unprepared families for home care; Difficulty access and follow-up in Primary Health Care services; Difficulty in including children in social interaction; and Positive reaction of the family towards adversity.*

- *Unprepared families for home care*

Regarding the lack of preparation for home care, the families did not feel oriented about the general care with CSHCNand,

in some cases, the information received, referred only to the technological devices of maintenance of life.

No professional guides you so much about the care you have to have with them, do not they?(Mother of W, 11 years old and of L, 03 years old)

Never has any health professional advised me or taught me how to take care of (child's name), or told me how I was going to take care of him at home [...] nor his gastroenterologist, who placed the probe, showed me how I had to clean it... (Grandmother of R, 02 years old)

[...]then the nurse explained exactly the way to handle the probe, the way the milk droplets passed and then how to clean; but only about it [...] but the rest we learned by ourselves. (Grandmother of L, 07 years old)

At that time I did not have a pediatrician to talk to me like this' Look, you're going to do this, this and that[...] as it was by SUS, he did not have a private doctor!First, it was the one who got him on duty, and then the one that was discharged was another [...] she (the doctor) did not tell me anything, she just told me that this day I would have to take the stitches off the valve and do the dressing, so much so that I did not know how to take care of. (Mother of B, 08 years old)

The lack of this information and the need to obtain it made the family turn to the professionals of the special school, who were more willing to inform it, for example, about adequate mobilization of the child, measures of stimulation for neuropsychomotor development and guidelines for seeking professionals specialized in specific situations. These guidelines helped the family to deal with certain daily challenges with the child, as seen in the following statements:

[...]it was at the ANPR [Associação Norte Paranaense de Reabilitação - Northern Paranaense Rehabilitation Association] that I began to understand my son's special needs, right? Because they talk more there. (Mother of B, 08 years old)

I have more knowledge because of the school (ANPR) today, right? They explain to us how we do to better care for them, even in the physiotherapy part of the home. They even give us a massage course.(Mother of W, 11 years old and L, 03 years old)

We did not know what to do during seizures.[...]I would rush with him straight to Santa Casa(T.N - Santa Casa da Misericórdia is a brotherhood whose mission is to treat

and support the sick and disabled, as well as assisting "exposed" - newborns abandoned at the institution)[...] then his teacher from the school told me to ask the doctor if he needs to go to the hospital every time the crisis occur. (Grandmother of L, 07 years old)

These statements indicate that not always the lack of resolution is related to the health service's structure itself, but to the lack of preparation and sensitivity of the professionals who work in it, impacting the provision of care often cold and inhuman to this clientele.

[...]so I would take him straight to the municipal hospital[...] and I used to tell professionals, 'look, he's special and he's in a lot of pain', but they did not care[...]then we decided to pay the health insurance for him, even though the issue of money was difficult [...] so, by the SUS, the time that we most needed, they did not answer. We never got the exams. All this was also due to the lack of good will by the doctors. (Grandmother of L, 07 years old)

Look, I got to the Santa Casa at four o'clock in the afternoon and I left eight o'clock at night [...] and he was burning with fever, then the nurse who answered me put the bracelets there of priorities, and said that he was not a priority in the care [...] now you tell me, how are we not priority in the care?(Mother of J, 08 years old)

- *Difficulty access and follow-up in Primary Health Care services*

Regarding the access and follow-up of CSHCN and their families by the Primary Health Care professionals, it was evidenced that the attendance of the team, when it occurs, is restricted to the visit of the Community Health Agent seeking information on the child's health status:

No one from the health center ever came to guide us, nor did the nurse visit. I'll go check it out, right? I have diabetes and those meetings they hold, I already told them that I have no condition to participate because of it. Because they take too long, this is not the case for just one hour! So I cannot stay. (Grandmother of L, 07 years old)

[...]at the beginning he came, you know [...] from when he was born, once the doctor came [...] he only performed that one-year follow-up, but [...] the Community Health Agent comes to the gate and asks if everything is okay with the child, size and weight; and next month he would come again, and when he could not come here, he would call on the phone. And now, with the younger sister of J.V.M.M [Down Syndrome], we're going through the same thing. (Mother of J, 08 years old)

We obtained Information about the rights of CSHCN, both regarding the acquisition of resources and the management of child care through other parents who experienced similar situations.

Much information is missing on children's rights and health service duties [...] when I went to the health center to request the milk for the L, they did not know to inform me how I should proceed, because the social worker was on maternity leave. So they asked me to come back in six months [...] then you realize that neither the health service knows how to report how you do to get access to the things you need. (Mother of J, and of L, 04 years old)

I used to buy the equipment and syringes from G, then one day when he was about six months old, I was waiting for an appointment and the mother of a child there told me 'Grandma, but you can get these things all at the health center', [...] We kept for over a year buying milk [...](Grandmother of G, 02 years old)

What I think is more difficult is that they are little informed of the rights issues they have. We do not know what rights they have, we learn more by talking to parents [...] then, talking to a father, he told me that there was an exemption system from the government of IPI (T.N. - IPI means Taxes over Industrialized Products), ICMS (T.N. - ICMS means Tax on Operations related to the Circulation of Goods and Provision of Interstate and Intermunicipal Transportation and Communication Services)and IPVA(T.N. - IPVA means Property Tax on Motor Vehicles) to buy an adapted car that would enable me to do all this[...]. (Mother of J and L, 04 years old)

The lack/limitation of physical space and flexible schedules of health professional's care makes it difficult to participate and care for the family, preventing it from being adequately instrumented to deal with the daily demands of child care. These families require close listening of trained professionals so that they can talk about their feelings and receive guidelines that are appropriate to their needs. Not to find openness to the dialogue by the professionals intensifies the suffering of the family that cannot share their experiences and desires.

I went to the health center and I asked for a psychological help there, but I did not get much, because there are no flexible hours [...]. I went for a month, but I gave up, she did not pay much attention to what I felt [...] Could not the psychologist be flexible with the schedule or come here? And the nurse to guide me when my son has seizure? (Mother of P, 10 years old)

But deep down, we suffer [...]you know, no one is ready to

listen to what we have to say. Then you end up not opening up yourself [...] (Mother of B, 08 years old)

- *Difficulty in including children in social interaction*

The family also encounters difficulties regarding the inclusion of the child in social life and the lack of support services that facilitate the inclusion and social life of both the child and himself, which presents itself as another challenge.

The biggest difficulty I think I have is to go to places with the R.S, because it's not everywhere I can go! Where you go, there is a step. Sometimes you go to a store or a restaurant and do not have an access ramp, you will pass with the chair and it is tight. (Mother of R, 09 years old)

In the trajectory of child care, the family faces prejudice and challenges to perform basic care in public places, needing to deviate from the attention of the people and greater privacy. The family perceives a pitiful glance and attitudes that demonstrate society's repulsion towards the child.

You know, sometimes we would go out with him and give his time to breastfeed, and I had to get to a hidden place, right? Because there are those people who look and pity, and others who are disgusted by that[talks about administering the milk with a syringe by gastrostomy] [...]. People do not take it when you take them out. There is a lot of prejudice!(Grandmother of L, 07 years old)

- *Positive reaction of the family towards adversity*

As for the family's positive reaction to adversity, it was found that even with all the difficulties and challenges encountered, family caregivers demonstrated in their reports that they can respond positively to adversity. This reaction happens with the search for support to overcome mishaps, which is found through the exchange of experiences with other families exposed to similar experiences, as demonstrated by the following statements.

[...] It's gratifying, you know? We celebrate every little thing, every little gesture they make, and that for others, it's nothing! For us, it's a lot! It's a victory[...]. Our support network is the mothers of ANPR (Mother of J and L, 04 years)

L is a very important child in our lives. [...] it is there at ANPR that one mother helps another, we speculate how each one does [...] (Grandmother of L, 07 years old)

Spiritual support to overcome difficulties is perceived by caregivers as the divine empowerment for child care, translated by the help of people, financial resources and the strength to carry on.

God provides for the people he chooses to be the mother, because you give up too much, but you do not miss what you give up! It's very rewarding, other things look pretty small. (Mother of R, 09 years old)

Because God cares for us, you know? [...] God surrounds you with people he knows you will need them. [...] in the financial, in the sentimental scope, in everything [...] so God will surround you with people like that, so that when you fall, you can get up. (Mother of B, 08 years old)

Families see in other families living in the same situation an important source of strengthening and support. On the other hand, it can be seen in the statements that they coexist with innumerable difficulties related to health services, distant relationship with professionals, lack of or little access to information on children's rights.

DISCUSSION

Family caregivers participating in the study reported that at no point they were prepared by health professionals to perform care with children at home. When asked about the guidelines received at the time of hospital discharge, they reaffirmed that they received basic information about some care related to management of technological resources, which children use. We should emphasize that there were few references to nursing professionals as support agents or information regarding children care at home. When they mentioned these professionals, they cited curativist care, centered on the use of technology and only in a hospital environment, corroborating the study carried out in Santa Maria/RS ¹¹.

The fact that the family is not guided to carry out home care to the child indicates that it is not recognized by the health service as unit of care and main caregiver. The use of the PFCC assumptions as a basis for professional practice would enable changes in the care provided to families and, consequently, the improvement of the care offered to the child. Recognizing the family as the custodian of care, apprehending their needs and demands, equipping them to perform procedures, and establishing a partnership between professional and caregiver in different settings are essential points for health care¹⁵.

In this study, we verified that the nurse is little present in the family experience and, as a professional, assumes a role basically related to the curative guidelines in the hospital environment, failing to optimize the family potential and to direct educational actions that promote training care for the family at home.

The special school attended by children is cited as an important support network where families experiencing similar situations can meet and exchange experiences. In addition, in this institution work several health professionals, most of them formed by physiotherapists, speech therapists and occupational therapists, aimed at rehabilitation. However, in addition to its educational and rehabilitation role, the institution also assumes

the role of guide and promoter of family health.

The nursing team should be the main source of scientific reference in the preparation of the family to perform care for the child at home. For this to occur, however, professionals need to be aware of their home and to recognize the home as an environment for the practice of health care and the family as the main caregiver¹⁴.

Nurses can use some educational components to promote effective family functioning. They can, for example, explain the treatment approach, differentiated strategies for care delivery, emphasizing the importance of maintaining flexibility so as to allow a family life as normal as possible. And also guide families in ways that can facilitate the transportation of the child, including carrying out rehabilitation activities¹⁸. In this sense, and considering the difficulty they face in transporting these children, it is essential that these families are informed about the right to acquire vehicles under special conditions.

In order to encourage professionals to recognize the family as a context of care, it is necessary for government agencies and health managers to become aware of the importance of family participation and to program policies, adequate spaces for care, and provide resources that professional practice, having the PFCC as its philosophy¹⁵.

The adoption of this assistance philosophy can bring benefits to patients, families and the institution. This was observed when a Georgia academic medical center in the United States based its care on this model and found that engaging the family and the patient in the care provided an improvement in the quality of care provided, positive impacts on the satisfaction of users and professionals, institution's finances and the greater demand for the service by the population¹⁹.

Therefore, providing families with quality nursing interventions and effective health care makes it possible to take care of the physical and psychological health of children and their family, and this support is fundamental to continue the treatment of the child²⁰.

When family caregivers are trained and prepared to perform the care for CSHCN at home, the child presents positive responses in their development and in the performance of basic daily activities, social inclusion and self-care practices. Interventions that take into account possibilities and limits of the caregiver and the family as a whole, their support network and physical structure, contribute to the fulfillment of their daily demands and the care for the child. Thus, thinking together with the family the necessities of required and possible adaptations will provide innumerable benefits to the child - and his family - and is a simple, efficient and low-cost activity for health services²¹.

The PFCC model envisages that government agencies need to institute sound health policies and programs that are tailored to the needs of families and provide emotional and financial support¹⁵. However, this is not the reality reported by the families of this study, according to which the CSHCN are usually faced with little resolving and even with the difficulty of accessing public health services. This fact leads families to have their

budget compromised when paying for a private health insurance in order to obtain, in a more agile way, better access to exams when necessary and greater quality in the care and treatment of health interurrences - which does not always happen.

In this sense, a study carried out in the United States, for example, demonstrated the dissatisfaction of CSHCN families with a private health insurance due to the lack of doctors available for home care, transportation problems or unavailability for services in specific areas²².

The PFCC proposes an alliance between families and health professionals to jointly establish the real needs of the child and family caregivers in order to develop strategies aimed at improving the quality of care provided and also to convince managers to make available resources for the implementation of these strategies¹⁵.

In this study, it was also found that even families having access to the Basic Health Unit for the removal of materials and inputs used and needed for childcare²³, the Family Health Strategy (FHS) of the health conditions of these children. Families report that they are only visited by the Community Health Agent, which demonstrates a certain deficiency in the monitoring of the child in the context of the community in which they reside.

It should be emphasized that Primary Health Care is the gateway to the health system, which must guarantee, with resolve, the universal care of the population. However, families are often exposed to the precariousness of the service and lack of professional commitment, and it is necessary that they themselves seek alternatives to solve their problems. According to some authors, the quality of the structure of the health unit for the care of the child and his/her family, and their follow-up of comprehensive health, have a positive impact on reducing the worsening of the disease and on its health condition²⁴.

Lack of awareness and lack of guidance on the rights of the child also permeate family experience in all care settings and care trajectories, with little access to information on existing public policies for the care of children under special health conditions. In general, they learn about these policies through other parents who have similar conditions. The absence or even precarious accessibility of public spaces, the difficulties of locomotion and the lack of preparation of the society to include the child with special needs of multiple and complex care in social life is a persistent challenge in the experience of the families.

Thus, the families of this study referred to the unpreparedness of society to accept the realization in public of some care that needs to be given to these children, showing social exclusion and disrespect towards this population.

Thus, intersectoral articulation involving educational, social, accessibility and health spheres with the community is fundamental to promote the quality of life of the population. Understanding the real needs of people with disabilities in the context of society enables services to direct their attention in order to provide a better quality of life for the population. This can be achieved, for example, with more frequent home visits by the FHS team, the activities of groups living together, the

dissemination of information and rights, and inclusive social and cultural activities in the neighborhood and even in the city²⁵⁻²⁶.

In this sense, the FHS teams “can constitute privileged spaces for the recognition of the living conditions of the population with disabilities and the promotion of universal access to assistance”^{25:177}. And, in particular, for the exchange of information between those who experience similar situations of life.

Faced with the demands and challenges presented, the family reorganizes its dynamics and seeks to live together according to its possibilities, but in a positive way in relation to the condition of CSHCN. In this setting, religiosity and spirituality are sources of support, and families celebrate each child's evolution, however small it may appear in the eyes of others. Thus, the existence of listening spaces with professional orientation would be fundamental so that the relatives could share their fears and anguishes, as well as their experiences with the chronic condition of the child²⁷.

Although the PFCC model existed for about 50 years and presented irrefutable advantages, such as the family's full involvement in care, it is observed that its premises are not approached in nursing practice with these children and their families, especially in the field of Primary Health Care.

STUDY LIMITATIONS

The study was carried out with family caregivers of CSHCN enrolled in a special school in the municipality of Maringá/PR, and may not reflect the reality of the CSHCN of the municipality that are not enrolled in that institution. Because it is a qualitative study, it is not intended the generalization, but its results should serve as a subsidy for professionals to reflect on their practices and seek, through Permanent Education, the necessary training to accommodate these children and their families, considering their singularities.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The challenges of CSHCN's family caregivers identified in this study are experiencing numerous difficulties, such as fears and yearnings, including lack of preparation for home care; the little resolving; the difficulty of access and follow-up in Primary Health Care services; and the little knowledge about the rights of CSHCN. These caregivers also face the absence or limitation of support services and the unpreparedness of the society to receive/accept children with special needs of multiple, complex and continuing care at home.

However, families are willing to continue in the face of adversity and daily challenges, and report that the support of other families experiencing similar situations and spirituality is fundamental to this overcoming.

Finally, nursing professionals lack training that allows them to transcend hospital technical care and develop a care practice based on care centered on the patient and the family. To consider the family as a unit of care is to recognize its protagonism with

the child. And, besides helping it to understand the disease and its interfaces, it favors its empowerment and autonomy in the performance of a care that has as its purpose the child's well-being and quality of life.

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