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Home care service for children/adolescents with special health care needs: family perception

Cuidados do Serviço de Atenção Domiciliar às crianças/adolescentes com necessidades de saúde especiais: percepção familiar

Servicios de atención de salud a domicilio a niños/adolescentes con necesidades especiales de salud: percepción familiar

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ABSTRACT

Objective: To apprehend the family's perception of the care provided by home care services to children and adolescents with special health needs.

Method: Qualitative, exploratory-descriptive study, carried out with 15 family members of children and adolescents with special health needs served by Home Care Services in seven municipalities in Paraíba, in 2021, selected from nine municipalities identified by previous studies. Data were collected using semi-structured interviews carried out remotely through telephone calls. The empirical material was subjected to Inductive Thematic Analysis and interpreted in light of the concept of health vulnerability.

Results: The Home Care Services facilitate minimize the health vulnerabilities of these children and adolescents and their families as they facilitate access to the actions and services of the Health Care Network, provide humanized care focused on promoting health and strengthening bonds, as well as how, they facilitate family decision-making at home regarding users' health needs.

Final considerations: The actions of these services permeate family daily life, enabling the expansion of care practices for family members/caregivers considering their limitations and improving the coordination of Health Care Networks to guarantee comprehensive care.

Descriptors: Home Care Services. Child. Adolescent. Chronic Disease. Caregiver.

RESUMO

Objetivo: Apreender a percepção da família acerca dos cuidados prestados pelos serviços de atenção domiciliar a crianças e adolescentes com necessidades de saúde especiais.

Método: Estudo qualitativo, exploratório-descritivo, realizado com 15 familiares de crianças e adolescentes com necessidades de saúde especiais atendidos por Serviços de Atenção Domiciliar de sete municípios da Paraíba, Brasil, em 2021, selecionados de nove municípios identificados por estudos prévios. Os dados foram coletados com uso de entrevista semiestruturada realizada remotamente por meio de ligações telefônicas. O material empírico foi submetido à Análise Temática Indutiva e interpretado à luz do conceito de vulnerabilidade em saúde.

Resultados: Os Serviços de Atenção Domiciliar minimizam as vulnerabilidades em saúde dessas crianças e adolescentes e seus familiares à medida que facilitam o acesso às ações e serviços da Rede de Atenção à Saúde, prestam um cuidado humanizado e centrado na promoção da saúde e fortalecimento de vínculos, bem como, facilitam a tomada de decisão familiar em domicílio quanto às necessidades de saúde dos usuários.

Considerações finais: As ações desses serviços permeiam o cotidiano familiar, possibilitando a ampliação das práticas de cuidados aos familiares/cuidadores considerando suas limitações e melhora da articulação das Redes de Atenção à Saúde para garantir um cuidado integral.

Descritores: Serviços de Assistência Domiciliar. Criança. Adolescente. Doença Crônica. Cuidador Familiar

RESUMEN

Objetivo: Conocer la percepción de la familia sobre la atención prestada por los servicios de atención domiciliaria a niños/adolescentes con necesidades especiales de salud.

Método: Estudio cualitativo, exploratorio-descriptivo, realizado con 15 familiares de niños y adolescentes con necesidades especiales de salud atendidos por Servicios de Atención Domiciliaria en siete municipios de Paraíba, en 2021, seleccionados entre nueve municipios identificados por estudios previos. Los datos fueron recolectados mediante entrevistas semiestructuradas realizadas de forma remota a través de llamadas telefónicas. El material empírico fue sometido a Análisis Temático Inductivo e interpretado a la luz del concepto de vulnerabilidad en salud.

Resultados: Los Servicios de Atención Domiciliaria minimizan las vulnerabilidades en salud de estos niños, niñas y adolescentes y sus familias, ya que facilitan el acceso a las acciones y servicios de la Red de Atención en Salud, brindan una atención humanizada enfocada a promover la salud y fortalecer los vínculos, además de facilitar la decisión familiar. -hacer en casa teniendo en cuenta las necesidades de salud de los usuarios.

Consideraciones finales: Las acciones de estos servicios permean el cotidiano familiar, permitiendo ampliar las prácticas de cuidado a los familiares/cuidadores considerando sus limitaciones y mejorando la coordinación de las Redes de Atención en Salud para garantizar una atención integral.

Descriptores: Servicios de atención domiciliaria. Niño. Adolescente. Enfermedad crónica. Cuidador familiar.

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INTRODUCTION

Child health care in Brazil has been characterized by scientific and technological progress, leading to a reduction in neonatal death rates and an increase in the survival of preterm children and children with chronic diseases. Thus, public policies moved from a biomedical model to another model aimed at comprehensive care, with disease prevention, health promotion and protection actions, favoring effective vaccination coverage and reducing malnutrition and infant mortality[1].

Advances in child care made it possible, after an international consensus[2] and deliberation by a Brazilian working group, to define, in Brazil, Children with Special Health Needs (CSHCN)[3]. This definition was intended to characterize a distinct group of children at greater risk of developing chronic conditions and functional limitations due to physical, behavioral, emotional and developmental disorders, which may result in the need to use health services beyond those generally required by children[2].

In Brazil, one in every four families has a child with some special health need, resulting in a prevalence of 25.3%[4]. These children usually depend on health devices and, often, on complex home care, which is provided by their families, which results in challenges such as fear and anxiety regarding home care, feelings of guilt about the CSHCN's illness, and social isolation, difficulties in accessing health services, medicines and equipment, as pointed out in an international review study[5]. Therefore, families are left in a situation of social, individual and programmatic vulnerability, which is reflected in their care actions for these children and adolescents[6].

Health professionals who provide home care are needed to assist with the care demands of CSHCN and the vulnerabilities of their families. This is shown in a study carried out in Sweden, with family members of children assisted by a home service, who reported that the work of these services, in addition to being beneficial to the CSHCN, it is also convenient for the parents, as it does not interfere with their daily activities and social relationships; it generates feelings of satisfaction with their children's improvement; it establishes a favorable environment for recovery, with safety and bonds of trust between family members and health professionals and promotes familiarization with complex procedures[7].

Regarding home care, the Brazilian government established the "Best at Home" Program, in which Home Care (HC) is the responsibility of the Home Care Service (HCS) [8]. HC encompasses rehabilitation actions, palliative care, health promotion, disease prevention and treatment, reducing episodes of readmission and infectious conditions among CSHCN, and is jointly responsible for care with family members[9].

Studies characterizing HCS pointed out some challenges in the care provided to CSHCN and their families in two Brazilian states. In Paraíba, the following challenges were identified: failure to comply with the minimum working hours required by the ordinance that regulates these services, unavailability of the service's own transport, which makes it impossible for users to travel within the HCN, and the lack of a direct means of communication between family members and professionals for teleconsultations[10]. In Mato Grosso, the challenge faced was the lack of adequate health literacy, as only 37.5% of the HCS provided guidance to family members and reassessed them by asking questions about the care that should be provided to CSHCN[11].

CSHCN face the most diverse vulnerabilities related to their fragile health and access to health services that are not very effective in meeting their specific demands[12]. Therefore, the Ayres' theoretical framework[13] was adopted to guide this concept, in order to generate reflections on the health care processes of CSHCN and their families by the HCS. Vulnerability refers to the susceptibility of any person to health problems and damage. It is subdivided into social vulnerability, when it involves the socioeconomic situation; individual vulnerability, when it affects the personality formed from social interaction; and programmatic vulnerability, when it relates to access to public health actions, services, programs and policies.

A study identified the health vulnerabilities of families and their CSHCN in the programmatic scope related to the difficulty of accessing the services of the Health Care Network (HCN), in the individual scope related to the clinical fragility of the child and adolescent and the overload of the family member and in the social scope related to the low education, job abandonment and low income[6]. It is clear that home care for CSHCN imposes challenges and difficulties on family members. Therefore, families and their vulnerabilities must be better understood and emphasized to ensure the quality of life of CSHCN and improve the quality of care offered by HCS. The present study therefore aims to understand families' perceptions of the care provided by home care services to children and adolescents with special health needs.

METHOD

Qualitative, exploratory-descriptive study, arising from a master's thesis in nursing and linked to a multicenter research funded by the National Council for Scientific and

Technological Development (CNPq), conducted in seven Brazilian states (Paraná, Rio Grande do Sul, Santa Catarina, São Paulo, Mato Grosso do Sul, Paraíba and Maranhão). The Consolidated Criteria for Reporting Qualitative Research (COREQ) [14] was used to guide and standardize reports from this and other research developed in other states.

The scenario of this study was HCS types 2 and 3. Nine municipalities in the state of Paraíba that at the time assisted CSHCN were included and were listed based on previous studies linked to the multicenter project, namely, Conceição, Cajazeiras, Monteiro, Caaporã, Pedras de fogo, Conde, João Pessoa, Guarabira and Queimadas, of which five were from the inland of the state and four from the metropolitan region, seven were small, one was large and one was medium-sized.

Family members and/or caregivers of CSHCN assisted by HCSs in the nine selected municipalities of Paraíba participated in the study. The inclusion criteria were: being 18 years of age or older; being a family member and/or caregiver of CSHCN assisted by HCS types 2 and 3; having been assisted at least five times, regardless of the age of the CSHCN. This frequency was considered necessary so that participants could have experienced HCS and had elements to talk about the care provided by the services. The exclusion criteria were: not having access or technological ability to handle the Free and Informed Consent Form (ICF) link and having non-existent telephone numbers.

Data were collected remotely between June and September 2021, through telephone calls made by the first author, a nurse and master's student, previously trained to develop the research. Participants were selected by convenience sampling. Initially, the researcher made seven telephone contacts and two face-to-face contacts with the coordinators or professionals of the multidisciplinary team of the HCS, who, after being aware of the research proposal, made available the telephone contacts of the family members/caregivers of the CSHCN assisted and facilitated the approach between the main researcher and the potential participants.

Of the nine municipalities contacted, two did not participate of the research, as each of them had only one registered CSHCN who was discharged before data collection began. Then, 19 contacts of family members/caregivers distributed across seven municipalities were obtained. Each potential participant was invited by phone call or via messaging application (WhatsApp®) to collaborate with the study. In case of acceptance by the participant, the objective of the research was explained and a single semi-structured interview was scheduled. In total, three family members/caregivers refused to participate and one of them had a non-existent cell phone number, resulting in 15 participants.

The interviews were conducted via telephone operator and recorded using free versions of the digital applications Super Recorder or Mimik Lite: Call Recorder and were based on a guide, which was previously discussed and standardized for replication in all research sites of the multicenter project. The interview audios and the ICF were stored by the main researcher.

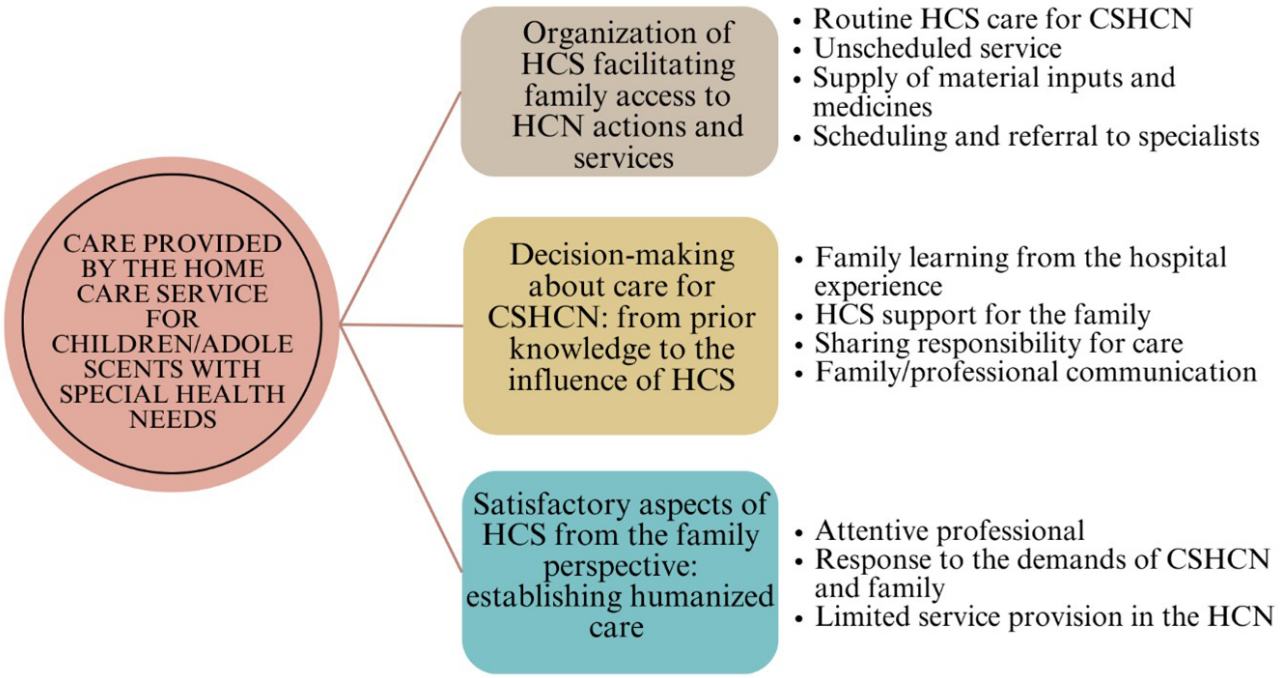
The interview guide included the following questions: How do you perceive the care offered to [child's name]?; When you receive health care for [child's name] at home, what are the reasons?; Do the professionals make time for you to talk about your problems or doubts?; Do the professionals guide you on what care you should take at home and how to do it?; What would you change to improve the health care service for children like [child's name] in the municipality?

According to the data saturation criterion[15], the collection was ended when all participating family members were interviewed, with no repeated interviews. The recordings totaled 397 minutes and were transcribed verbatim and not returned to the participants.

The empirical material was interpreted from the perspective of the concept of Vulnerability[13], through Inductive Thematic Analysis (ATI)[16], according to its six stages, as follows: 1. Becoming familiar with the data, with listening and transcription of the interviews; 2. Generation of codes, with identification and organization of the data extracts and their respective color codes; 3. Definition of potential themes, grouping the codes according to their similarities; 4. Review of the themes, carried out by two researchers, in order to identify important distinctions between the study theme and the definition of health vulnerabilities; 5. Definition and naming of three themes and their respective data coders, totaling 11, and construction of the thematic map (Figure 1); 6. Preparation of the report. No software was used in this process.

The present study was approved by the Ethics and Research Committee, under CAAE No. 45615521.8.0000.5188 and Protocol No.4,736,299, in accordance with the ethical aspects in force in the country for research with human beings. Before the interview, the ICF was sent via WhatsApp® to all participants, using a Google form. All participants signed the ICF. For participants who reported having difficulty reading and understanding the term, a telephone call was made in which its content was read and explained by the researcher; in these cases, acceptance was recorded in audio, in addition to the virtual signing of the ICF. To guarantee the anonymity

Figure 1 – Thematic Map of the themes based on the analysis of family members' perceptions of care for CSHCN by HCS in Paraíba. João Pessoa, Paraíba, Brazil, 2022



*HCS – Home Care Service
† HCN – Health Care Network
‡ CSHCN – Child with Special Health Needs
Source: Elaborated by the authors.

of family members, their speech extracts were identified with "F" and their CSHCN with "C", and numbered according to the order in which the interviews were conducted.

RESULTS

The study participants were 14 mothers and one father of CSHCN. Of these, two lived in rural areas and 13 in urban areas, 10 were married and five were single. Regarding education, five completed high school, one completed higher education and nine did not complete their studies. Eleven family members earned one minimum wage and four earned between one and a half and two minimum wages. Regarding the CSHCN, four were adolescents and 11 were children, five were female and 10 were male. As for the dysfunctions, they were of neurological, genetic or resulted from accidents. The average time of care provided by the HCS was 2 years.

The interpretation of the results and the construction of the thematic map made it possible to identify three themes and to perceive the interrelationship between the programmatic, social and individual vulnerabilities of family members in the context of HC. This interrelation is evident in the explanation of the following themes: 1) Organization of the HCS facilitating family access to the HCN actions and services; 2) Family decision-making regarding care for CSHCN: from prior knowledge to the influence of the HCS; 3) Satisfactory aspects of the HCS from the family's perspective: establishing humanized care.

Organization of HCS facilitating family access to HCN actions and services

Family members of CSHCN realize that the HCS routine care is organized according to the demands of the service and each specific situation. When they need rehabilitation with speech therapists and physiotherapists, the frequency is one to three times a week, and they are always accompanied by a nurse, if necessary. In turn, doctors, nutritionists and social workers provide care fortnightly, monthly or whenever the CSHCN need such care. For family members, the way the HCS is organized makes scheduling weekly appointments more flexible, ensuring the continuity of the CSHCN's rehabilitation process.

> *They* [health care professionals] *come here every week, speech therapists and physiotherapists. The nurses come*

too. [...] *The doctor only comes when it is really necessary* [...] *The nutritionist comes once a month to check on her* [C6] *and give me an expert report on the milk.* (F6)

They always come on Fridays or Mondays, if I need assistance on Monday, they [HCS professionals] *come on Monday; if I don't need it, they come on Friday.* [...] *They can't come every week, but every 15 days, the HCS professional comes to check on him.* (F5)

Now it's all set. They [the HCS professionals] *set the day for the visits. On Thursdays I know they're coming, so I bathe the child, put the mattress on the floor and wait for the health professionals. On Mondays, it's the same.* (F14)

In two municipalities, the HCS provides 24-hour service. According to family members, this enables care to CSHCN in clinical emergency situations. Furthermore, the HCS offers remote assistance and telephone calls for guidance and consultation requests that are not part of routine services. This brings security and comfort, as family members have the guarantee of care, especially residents of rural areas, exposed to social vulnerability, due to the difficulty of the HCS in accessing the residence and/or the lack of transport to move around with their CSHCN.

When he [C5] has a slight fever, needs some medication, they [HCS] *come to examine the boy* [...].*I schedule the appointment by cell phone, I speak to the girl* [at the HCS desk] *by cell phone. In fact, I have never been to the place where they work, contact them by cell phone.* (F5)

They are on call 24 hours a day. The best thing is that it is at home [HCS] *and it is 24 hours [referring to the operation]. It could be Saturday, it could be Sunday, it could be a holiday, if the oxygen has run out, if he* [C10] *needs medication, the service is 24 hours a day. There is always someone* [HCS professional] *available.* [...] *At night, they* [HCS] *always come. It's just that since we live on the farm, when it rains, access is very difficult, there is a lot of mud, and there are frequent power outages* (F10)

For family members, the HCN makes it easier to obtain supplies and medications. This reduces spending on these materials and prevents the families from needing to travel to services specialized in the distribution of medicines located in cities that are hubs in the health region, making access difficult for those who live in inland cities. When they do not provide all the necessary supplies and medicines, the HCSs carry out intersector coordination to ensure them, with emphasis on their efforts to reduce the existing programmatic vulnerability.

It's good because we get a lot of stuff: probe, gauze, gloves, lidocaine, which I also use. [...] *I need practically four kits a day, because* [a bladder catheter] *is needed every 6 hours, and if I were to buy one, it would be very expensive. So, the HCS is excellent, both in terms of assistance and health.* (F1)

In the Best at Home [HCS] *program, medications are distributed until now. The doctor prescribes them, and the Best at Home program attendants get the medication from him.* [...] *For controlled* [medications], *the doctor writes the prescription, and I go to the CAPS [Psychosocial Care Center] to get it.* (F7)

I don't need to go out to do anything, they [HCS] *bring the control medication that the boy* [CSHCN 10] *takes.* [...] *In the past, I would get the trilexal and sabril at CEDMEX* [Specialized Center for Dispensing Exceptional Medications], *but not anymore, the Best at Home program* [HCS] *attendants get the medicines at the CAPS of [name of the municipality], which is also available.* (F10)

Most referrals and appointments for specialists are made by the HCS, favoring the referral and care of CSHCN in specialized care. When they are not referred, the families seek other health services on their own.

Everything [referrals] *is done by them* [HCN]. *Referral to a neurologist, urologist, etc. it's all on them. I don't have to go out. I just call them and tell them what needs to be done, that is, that he* [C10] *needs do see a neurologist.* (F10)

Nobody does that [referral to a specialist], they don't tell me anything. I only go there when she's sick, she has a GTT [gastrostomy tube] *inserted into her stomach, I go to the* [municipal] *hospital and am referred to the [referral children's hospital] and from the* [referral children's hospital], *she comes home and that's it.* (F9)

We go to the regulation sector of the department, take the request [for referral] *that we get at the post. Regarding the return inspection, we bring the return inspection from the specialist* [in the capital]. *Then we take it to the regulation sector, get the identification at the Family health program* (PSF) and take it to the regulation sector along with the child's documents. (F11)

Most of the time, the HCS organizes its actions to facilitate access by CSHCN' families to the HCN actions and services, providing care focused on health promotion and rehabilitation. This shows their commitment to alleviating programmatic and social vulnerabilities in health, making

the families of CSHCN feel welcomed and supported in home care. However, one of the statements above characterizes the absence of longitudinality of care and needs to be considered, as it shows that, in the health service to which that individual is linked, there is no flow within the network through the HCS.

Family decision-making about CSHCN care: from prior knowledge to the influence of the HCS

In the hospital environment, family members receive guidance on home care related to the modified habits of children and adolescents and feel confident in handling invasive devices. It is up to the multidisciplinary teams of the HCS to adapt care to the reality of each family, implementing rehabilitation actions, providing guidance on carrying out rehabilitation exercises to stimulate the development of CSHCN.

> *All the guidance they* [HCS professionals] *gave me was already known to me. Because I had already received guidance before too, before she* [C6] *was assisted by the HCS. As soon as she left* [name of hospital] *with the nasogastric tube, I was instructed on how to care for her. After the gastrostomy, I was instructed on how to dress her, how to clean the area properly, how to give her food, how to put her on* [the diet]. (F6)
>
> *He* [the HCS Physiotherapist] *said that I should move his joint, stimulate him, talk to him a lot, make him walk, make him play with the ball, to help. This professional told me to do a massage with oil, which is very relaxing, and take him to a pool bath, which is also very good, it's like swimming. Sometimes he talks a lot, he says that I should buy some things to put on the boy's spine, we already made the order.* (F12)
>
> *They* [HCS] *have already guided me on how to continue doing* [home care]. (F13)

In order to improve the care provided to CSHCN at home, a mother added that the HCS professionals in one of the municipalities investigated, in addition to carrying out care practices on patients, also include their family members, in order to strengthen them, giving them the health support they need.

> *There is also acupuncture. Whenever C10 has an acupuncture session, I also have an acupuncture session with the health care professionals. They give us full support too, because they say that there is no point in just taking care of the patient if the caregiver is also not well. They give all the support to the family, when necessary.* (F10)

HCS professionals expect families of CSHCN to share responsibilities for care provided at home after receiving guidance. However, family members report that they often fail to carry out the recommended practices due to lack of time due to household chores, having other children and fear of causing injury while handling the CSHCN.

> *I try, I just don't do* [physiotherapy exercises] *anymore due to lack of time, due to household chores, because here at home it's just me and my other daughter. So, I usually set aside a little time at night, around 8 pm, to do some therapies that she [the physiotherapist] does.* (F1)
>
> *Yes* [the HCS guides care]. *However, I'm afraid to follow the recommendations because her bones* [C15] *are very hard, and I'm afraid of hurting her,* [...] *so I don't move there much.* (F15)

Sharing responsibilities in the demand for care not only facilitates family-CSHCN involvement, but also promotes effective communication between family and HCS professionals. This favors the bonding relationship and active listening, so that there is an exchange of knowledge and clarification of doubts regarding care, information about services and coordination of services in the network.

> *They listen to me [the HCS professionals], they are so good. We also listen to what they say. They are very good.* [...] *When we don't know something, we ask them to find out if we are doing it right or wrong.* (F8)
>
> *If SAMU* [Mobile Emergency Care Service] *is used, we call the doctor* [from the HCS]. *If it is urgent and he is in another situation, we inform him of everything* [conditions of C7], *and he tells us to call SAMU, but first we inform everything to the doctor from Best at Home program* [HCS], *before informing any hospital doctor.* (F7)

By knowing in advance how to care for CSHCN, following the HCS guidelines and maintaining a good relationship with the professionals, the families can overcome their vulnerability. They then explain that they are able to make decisions about care safely. In these experiences, satisfactory aspects related to the care provided by the HCS are listed.

Satisfactory aspects of HCS from the family's perspective: establishing humanized care

The families of CSHCN are satisfied with the care they receive from the HCS professionals, and describe them as attentive, kind, welcoming, sensitive and patient, although the time provided for that service is very limited. They add that

some CSHCN become attached to these professionals and create bonds, as they receive humanized care, which transforms technical assistance into pleasant and fun encounters.

> *I like the service, they are very attentive* [HCS]. *They take good care of my little one, they treat her with great love. That's what matters to me, and I like their service.* (F6)
>
> *Yes, the current physiotherapist listens a lot, talks.* [...] *Honestly, she is an excellent professional. I can only say good things about her.* [...] *Despite everything, for the short time that she stays here, she [the physiotherapist] talks to him* [C3], *pays attention to him. He even likes her, she is really nice.* (F3)
>
> *I like him because he [physiotherapist's name] is a very good and charismatic person and C2 likes him. When he* [physiotherapist's name] *leaves, C2 cries. It's very good, I appreciate it very much.* (F2)

For family members, the positive changes brought about by the HCS were the changes in their routine and improvements in the clinical condition of the CSHCN. Thus, they ensured that most of the health needs of children and adolescents were met. This aspect, combined with the HCS's readiness to assist with home care, made it a service that meets the needs of CSHCN and families, addressing their health vulnerabilities within its responsibilities.

> *Whenever I need it, or if I feel something... She* [C1] *had diarrhea once, and the doctor* [HCS] *prescribed a medication for me to buy, or if it's a pain, sometimes, when she can't come* [HCS doctor], *she sends* [the prescription]. *So, I realized that I am very well taken care of.* [...] *Today, I see that it is enough [what the HCS does].* (F1)
>
> *After the Best at Home* [HCS] *program, C7's life changed, his routine changed, everything changed for the better, because what they can do for the families, for the patients, these* [HCS professionals] *who are assisting us now, they do.* [...] *I think C7 is much better after being monitored by the program.* (F7)

Families also perceive a shortage of good quality services in the HCN for CSHCN. This leads family members to seek philanthropic health services and to find these services only in the private sector, since the care offered by primary care (PC) is not always considered sufficient. They realize that these services have their limitations and recognize that the HCS is fundamental for comprehensive home care.

> *While it lasted, it was good [the HCS service]. Because, for example, many times, for those who are assisted by a school clinic, during the vacation period of that establishment, the only treatment available for the children is the HCS.* [...] *Because he [C4] is being treated in a Christian community here,* [...]. *And when this community goes on vacation, the service can be provided at the HCS, in December and January.* (F4)
>
> *As it was only at the USF* [Family Health Unit], *the doctor did not show up att the clinic from Monday to Friday, assistance was reduced, and there was a further worsening of respiratory problems.* [...]. *I hope they [HCS professionals] do not put an end to this program,* [...], *because it is of great importance for the lives of our children.* (F7)
>
> *Very good, I have nothing to complain about* [the HCS service]. *I can only thank them because they have helped my daughter a lot.* [...] *Because if we were to look for a service like this, we would have to pay, it would have to be private.* (F1)

The multidisciplinary teams at the HCS focus on providing assistance to CSHCN, to improve their clinical conditions. They break down the barriers of biomedical care, as they are concerned with the formation of bonds, trust and qualified listening, giving visibility to CSHCN, and their families, mitigating individual vulnerabilities related to feelings of insecurity regarding care, feel satisfied with the care received by the HCS. Furthermore, they perceive the HCS as essential within the HCN because it establishes continuous health care, with the aim of resolving or improving the health situation of CSHCN, as there is a programmatic vulnerability related to the difficulty of accessing the network's actions and services.

DISCUSSION

The analysis of family members' perception of the care provided to CSHCN by the HCS showed that the assistance provided by the multidisciplinary team complies with the provisions of Ordinance No. 825/2016[8], which regulates this service, offering appointments whose frequency depends on the health status of the CSHCN. Therefore, it is understood that flexible care, when established, can adapt to the specific condition and context of each family, being an important strategy to offer comprehensive assistance and minimize vulnerable situations experienced by the families of these children and adolescents.

In clinical emergency situations involving CSHCN, the HCS coordinates emergency services. However, there are units that operate 24 hours a day, beyond the minimum working hours defined in the Ordinance regulating these services[8], providing unscheduled emergency care to CSHCN. This organization indicates an advance in comprehensive

care by addressing the social, individual and programmatic vulnerabilities of the patients who make up this population, as some live in hard-to-reach locations and do not have adequate transportation to get around.

The provision of HCS operating 24 hours a day minimizes the contexts of programmatic vulnerabilities, facilitating access to the health actions of this service as it allows for the clarification of doubts and immediate guidance remotely, in situations of disease exacerbation. This is highlighted in an international integrative review study in which remote care enabled comprehensive assistance to CSHCN, providing family members with feelings of satisfaction, reducing unplanned hospitalizations and improving the quality of life related to children's health[17].

Remote care via telephone calls emerges as an important HCS care strategy for CSHCN, as the possibility of communicating with professionals remotely guarantees continuity of care. These actions help clarify doubts and provide guidance to family members, since face-to-face contact with the team is impossible due to the need for professionals to travel to users' homes[18].

Telehealth is an affordable and effective option for monitoring home care in pediatrics. At the international level, it has been discussed that this method, complementing face-to-face care, provides information to family members in different electronic formats, instantly meeting their needs, and expands people's access to health services, providing support to families of children with special health needs[19].

Our study found that HCS is a service that facilitates obtaining supplies and referrals, and also consolidates knowledge that allows the family to provide care and optimize spending. However, there are other HCS that face weaknesses and difficulties in completely dispensing these materials and supplying medications. These facts increase the programmatic vulnerability of CSHCN and their families in the context investigated.

The family becomes responsible for coordinating the care of CSHCN, seeking PHC, emergencies or hospitals, and faces difficulties in accessing the network's health services, leading to a fragmentation of care that results in greater risk of programmatic vulnerability and increased clinical frailty. Furthermore, obstacles to access to the HCN services, due to delays in referral to specialists, due to difficulties in establishing the diagnosis, are other limitations brought up by a study with family members of CSHCN in the cities of Santa Maria, RS and Ribeirão Preto, SP[20].

An international study carried out in a home care program in Illinois, United States of America (USA), revealed the importance of a reference professional for the families of CSHCN, through the coordination of care, with articulation of essential health services, enabling intersector actions that guarantee the provision of supplies and referrals[21]. The appointment of this professional to assist families at the national level would result in a HCS capable of making referrals and scheduling appointments with specialists efficiently, facilitating the therapeutic itinerary of families in the HCN and minimizing contexts of programmatic vulnerability, thus guaranteeing this population's access to the network.

It is necessary to promote coordination between primary and secondary levels of care to avoid overloading tertiary care, as well as maintaining an organized multidisciplinary team to facilitate family members' access to the HCN, enabling them to make decisions regarding the care required by their children on a daily basis.

In the process of hospitalization of CSHCN, family members learn to provide unique care, aimed at the needs of oxygenation, nutrition, hygiene, comfort and well-being. There is a need for a primary contact between the HCS team and these family members during hospitalization, for adequate follow-up care at home, given that family members require contact with a health team trained to meet their information needs, providing guidance and monitoring care, in order to encourage and prepare them for home care for CSHCN[22].

However, a study found that family members did not receive adequate discharge instructions, which focused only on maintaining life, through the handling of technological devices, but with gaps in the integral aspects of quality of life, which include stimulating neuropsychomotor development and the impact on changing the family's lifestyle habits to carry out specific care[5].

It is understood that the clinical conditions of CSHCN may be unstable and that new devices may be necessary, therefore, it is important to prepare the family for new learning demands[20]. Thus, the HCS has a valuable role in reinforcing prior guidance and complementing family members' knowledge gaps, as well as implementing rehabilitation actions, in accordance with Ordinance 825/2016[8].

Family members also perceive this service as an offer of family care, as at times, the care offered to CSHCN is also extended to caregivers. These actions are essential to minimize the vulnerability of caregivers of CSHCN who are subjected to severe emotional and psychological overload, which impacts their well-being[23].

Families play an important role in sharing care with the multidisciplinary HCS team in the CSHCN rehabilitation process. However, a study conducted in the USA indicates that family members of children with medical complexities did not perceive themselves as partners of health professionals in the care of their children. However, a study conducted in the US found that family members of children with medical

complexities did not perceive themselves as partners of health professionals in the care of their children. This makes it difficult to establish bonds, impacting the activities of these professionals at home and increasing health vulnerabilities[24].

In the present study, individual and social vulnerabilities were identified that interfere with the provision of care and rehabilitation by the families at home. This aspect is corroborated by the results of another international study[22] in which the implementation of the necessary care provided to CSHCN was difficult to adapt to family life, due to the psychosocial overload, the high demand for domestic activities, the management of complex care for CSHCN and the feeling of distress. Thus, when admitting a CSHCN, HC must structure its care, also including care of the family, providing guidance on the appropriate management of this child, through audiovisual resources and reassessing their previous knowledge and experience on the procedures that must be carried out at home, increasing co-responsibility for care[11].

It should be noted that a professional care plan shared with the CSHCN's family tends to improve and fill possible gaps in the knowledge of some caregivers about caring for their children[25]. This shared responsibility for care tends to promote more effective communication between the team and the family, especially when the latter has doubts about the provision of services at other points in the HCN[26]. Professional communication in health is an aspect that strengthens the construction of bonds with users, as well as contributing to the generation of trust in the service offered and to minimizing caregivers' anxiety, making them more open to sharing care and exchanging knowledge[7].

Family members demonstrated their bond with health professionals, which is a positive aspect of the service. Satisfaction with the service was perceived in reports of care provided in an affectionate manner, by a caregiver concerned with the clinical history of the CSHCN, with welcoming and active listening. It is concluded that not only dense and expensive technologies are necessary to guarantee the quality of care, as light technologies have great potential to improve care.

The benefit of relationships can be proven by the reports from family members that CSHCN form bonds with HCS professionals when they receive this type of care and express this bond through gestures and reactions that demonstrate their happiness. Furthermore, care provided at home tends to be a key aspect for building a sense of security, as there is a minimization of acute conditions and improvement in the daily activities of CSHCN and their families[27], which is very difficult for any other health device with greater technological density to promote.

HC also contributes to minimizing some health vulnerabilities, such as the lack of basic supplies: medicines, food supplements, materials used in procedures, among others. Beneficial transformations in the family routine and the readiness to respond to users' requests make the service effective and minimize the burden on caregivers, who often still have other family demands, which impact their quality of life[28].

Before receiving care through the HCS, the participants in this study said they had difficulty finding rehabilitation assistance in other HCN services, which led to restrictions on seeking philanthropic institutions, keeping them only with the support of primary care, which is sometimes inefficient. A study concluded that primary care does not accompany CSHCN during home visits and does not efficiently absorb spontaneous demand, failing to meet their needs and those of their families, making longitudinality unfeasible and causing families to seek emergency care services in clinical emergencies[20].

Philanthropic services, despite their full participation in meeting the demands of CSHCN, often offering care at a secondary level, with rehabilitation actions and specialized appointments, face obstacles in ensuring continuity of care and, at times, are not linked to the formal referral network of the HCN[29]. Therefore, home care provided by HCSs is very relevant, as family members mention the clinical improvement of CSHCN, as well as the welcoming approach to treatment, with positive changes in the routine and social and health contexts of this population. However, limited access to other HCN points exacerbates the context of programmatic vulnerability experienced by CSHCN and their families.

Home care for CSHCN plays an important role in ensuring comprehensive health care for this population group, including reducing aspects related to individual, social and programmatic vulnerabilities. Promoting comprehensive care while minimizing vulnerability contexts allows for the understanding of aspects that transcend the disease and extend to primary caregivers and other family members[30]. HC carries out assistance actions that, in addition to the technical management of care, involve managing the vulnerabilities experienced by CSHCN and their families, focusing on experiences of illness, promoting humanized care.

A limitation of this study is the fact that it was carried out during the COVID-19 pandemic, which affected the functioning of home care services, and this may have interfered with the participants' perception of the care received. Another limiting factor was conducting the research in a remote environment, given that it only reached a segment of the population in HCS that has access to the internet, limiting the transferability of the study findings.

FINAL CONSIDERATIONS

The families' perception of the care provided by HCS to CSHCN was that the service has sought to develop holistic and humanized care, based on each family's circumstances and their experiences in providing care at home. Social, individual and programmatic vulnerabilities, related, respectively, to living in hard-to-reach places, family members' fear of providing care at home and gaps in care in the HCN, were mitigated with the presence of the HCS.

The provision of care also focused on the family members of CSHCN, whether by the HCS itself or by referrals to HCN services, so that their limitations are also considered relevant for home care actions, is another aspect that still needs to be improved and evaluated by this service. It is also necessary to improve the HCN, through agreements between health regions, to enable access for these children and adolescents to the various points of the network, with guarantees of support for HCS professionals and CSHCN, to establish comprehensive care.

The testimonies of the CSHCN family members provide relevant contributions to the improvement of HCS for the care of these children and adolescents, as the potential and difficulties experienced in the daily HC are highlighted. Such aspects can guide the practices of professionals in the multidisciplinary team and support the development of public policies that benefit this population and promote comprehensive and equitable care in different municipalities.

REFERENCES

1. Branquinho ID, Lanza FM. Child health in primary care: evolution of Brazilian policies and nurses' performance. Rev Enferm Cent-Oeste Min. 2018;8:e2753. https://doi.org/10.19175/recom.v8i0.2753
2. Mcpherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, et al. A new definition of children with special health care needs. Pediatrics. 1998;102(1):137-9. https://doi.org/10.1542/peds.102.1.137
3. Bastos MPC, Santos AST, Ledo BC, Moraes JRMM, Cabral IE, Góes FGB. Children with special health care needs in a pediatric emergency service: a cross-sectional study. Rev Enferm UFSM. 2022;12:1-18. https://doi.org/10.5902/2179769269299
4. Arrué AM, Hökerberg YHM, Jantsch LB, Gama SGN, Oliveira RVC, Okido ACC, et al. Prevalence of children with special healthcare needs: an epidemiological survey in Brazil. J Pediatr Nurs. 2022;67:95-101. https://doi.org/10.1016/j.pedn.2022.08.013
5. Van de Riet L, Alsem MW, Van der Leest EC, Van Etten-Jamaludin FS, Maaskant JM, Van Woensel JBM, Van Karnebeek CD. Delineating family needs in the transition from hospital to home for children with medical complexity: part 1, a meta-aggregation of qualitative studies. Orphanet J Rare Dis. 2023;18(1):386. https://doi.org/10.1186/s13023-023-02942-9
6. Dias, BC, Arruda, GO, Marcon, SS. Family vulnerability of children with special needs of multiple, complex and continuous care. Rev Min Enferm. 2017;21: e-1027. http://dx.doi.org/10.5935/1415-2762.20170037
7. Castor C, Landgren K, Hansson H, Hallstrom IK. A possibility for strengthening family life and health: family members'lived experience when a sick child receives home care in Sweden. Health Soc Care Community. 2018;26(2):224-31. https://doi.org/10.1111/hsc.12512
8. Ministério da Saúde (BR). Gabinete do Ministro. Portaria nº 825 de 25 de abril de 2016. Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS) e atualiza as equipes habilitadas [Internet]. Diário Oficial da União. 2016 [cited 2019 Oct 11]; Seção 1:33. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2016/prt0825_25_04_2016.html
9. Carvalho AJL, Ferreira HM, Borges EF, Borges Junior, LH, Paula ALT, Hattori WT. Analyses of the effectiveness of a Brazilian pediatric home care service: a preliminary study. BMC Health Serv Res. 2019;19(1):1-7. https://doi.org/10.1186/s12913-019-4148-4
10. Cavalcante MEPL, Santos MM, Toso BRGO, Vaz EMC, Lima PMVM, Collet N. It is better at home: characterization of home care services. Esc Anna Nery. 2022;26:e20220001. https://doi.org/10.1590/2177-9465-EAN-2022-0001pt
11. Bezerra AM, Akra KMAE, Oliveira RMB, Marques FRB, Neves ET, Toso BRG, et al. Children and adolescents with special healthcare needs: care in home care services. Esc Anna Nery. 2023;27:e20220160. https://doi.org/10.1590/2177-9465-EAN-2022-0160pt
12. Cianci P, D'Apolito V, Moretti A, Barbagallo M, Paci S, Carbone MT, et al. Children with special health care needs attending emergency department in Italy: analysis of 3479 cases. Ital J Pediatr. 2020;46(1):173. https://doi.org/10.1186/s13052-020-00937-x
13. Ayres JRCM. Vulnerability, Care, and integrality: conceptual reconstructions and current challenges for HIV/AIDS care policies and practices. Saúde Debate. 2022;46(7):196-206. https://doi.org/10.1590/0103-11042022E714
14. Souza VRS, Marziale MHP, Silva GTR, Nascimento PL. Translation and validation into Brazilian Portuguese and assessment of the COREQ checklist. Acta Paul Enferm. 2021;(34):eAPE02631. https://doi.org/10.37689/acta-ape/2021AO02631
15. Campos CJG, Saidel MGB. Amostragem em investigações qualitativas: conceitos e aplicações ao campo da saúde. Rev Pesq Qual. 2022;10(25):404-24. http://dx.doi.org/10.33361/RPQ.2022.v.10.n.25.545
16. Souza LK. Pesquisa com análise qualitativa de dados: conhecendo a Análise Temática. Arq Bras Psicol. 2019;71(2):51-67. http://dx.doi.org/10.36482/1809-5267.ARBP2019v71i2p.51-67
17. Ferro F, Tozzi AE, Erba I, Dall'Oglio I, Campana A, Cecchetti C, et al. Impact of telemedicine on health outcomes in children with medical complexity: an integrative review. Eur J Pediatr. 2021;180(8):2389-400. http://dx.doi.org/10.1007/s00431-021-04164-2
18. Rossetto V, Toso BRGO, Rodrigues RM, Vieira CS, Neves ET. Development care for children with special health needs in home care at Paraná-Brazil. Esc Anna Nery. 2019;23(1):1-10. http://dx.doi.org/10.1590/2177-9465-ean-2018-0067
19. Camden C, Silva M. Pediatric Teleheath: opportunities created by the COVID-19 and suggestions to sustain its use to support families of children with disabilities. Phys Occup Ther Pediatr. 2021;41(1):1-17. http://dx.doi.org/10.1080/01942638.2020.1825032
20. Neves ET, Okido ACC, Buboltz FL, Santos RP, Lima RAG. Accessibility of children with special health needs to the health care network. Rev Bras Enferm. 2019;72(suppl-3);65-71. http://dx.doi.org/10.1590/0034-7167-2017-0899

21. Sobotka SA, Lynch E, Agrawal R. The role of care coordinators for children with respiratory technologies and home nursing. Pediatr Allergy Immunol Pulmonol. 2022;35(2):49-57. http://dx.doi.org/10.1089/ped.2021.0236
22. Brandt M, Johannsen L, Inhestern L, Bergelt C. Parents as informal caregivers of children and adolescents with spinal muscular atrophy: a systematic review of quantitative and qualitative data on the psychosocial situation, caregiver burden, and family needs. Orphanet J Rare Dis. 2022;17(1):274. https://doi.org/10.1186/s13023-022-02407-5
23. Almohalha L, Pereira V. El bienestar de los/as cuidadores/as de niños/as con y sin necesidades especiales. Rev Chil Ter Ocup. 2020;20(2):221-35. https://doi.org/10.5354/0719-5346.2020.53884
24. Yu JA, McKernan G, Hagerman T, Schenker Y, Houtrow A. Most children with medical complexity do not receive care in well-functioning health care systems. Hosp Pediatr. 2021;11(2):183-91. https://doi.org/10.1542/hpeds.2020-0182
25. Desai AD, Jacob-Files EA, Wignall J, Wang G, Pratt W, Mangione-Smith R, et al. Caregiver and Health Care Provider Perspectives on Cloud-Based Shared Care Plans for Children with Medical Complexity. Hosp Pediatr. 2018;8(7):394-403. https://doi.org/10.1542/hpeds.2017-0242
26. Procópio LCR, Seixas CT, Avellar RS, Silva KL, Santos MLM. Home Care within the Unified Health System: challenges and potentialities. Saúde Debate. 2019;43(121):592-604. https://doi.org/10.1590/0103-1104201912123
27. Foster CC, Fuentes MM, Wadlington LA, Jacob-Files E, Desai AD, Simon TD, et al. Caregiver and provider experiences of home healthcare quality for children with medical complexity. Home Healthc Now. 2020;38(3):138-146. https://doi.org/10.1097/NHH.0000000000000857
28. Pegorin TC, Léo MMF, Zuge SS, Brum CN, Rosa L, Conceição VM. Quality of life and mental disorders in caregivers of children with special needs. Rev Rene. 2021;22:e61471. https://doi.org/10.15253/2175-6783.20212261471
29. Farias AC, Maia ER, Costa MS, Moreira MRC, Oliveira JD, Pinto AGA. Outlining the therapeutic itineraries of children with disabilities in the professional health care subsystem. Rev Bras Enferm. 2022;75(3):e20210169. https://doi.org/10.1590/0034-7167-2021-0169
30. Lima PMVM, Fernandes LTB, Santos MM, Collet N, Toso BRGO, Vaz EMC. Atención profesional en atención domiciliaria para niños y adolescentes con necesidades especiales de salud: una revisión integradora. Aquichan. 2022;22(1):e2215. https://doi.org/10.5294/aqui.2022.22.1.5

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