

(De)constitution of the healthcare network of children/adolescents with special health care needs

(Des)constituição da rede de atenção à saúde de crianças/adolescentes com necessidades especiais de saúde

(Des)constitución de la red de atención de salud de niños/adolescentes con necesidades especiales de salud

Hentiele Feksa Lima^I, Diúlia Calegari de Oliveira^{II}, Caren da Silva Bertoldo^{III},
Eliane Tatsch Neves^{IV}

Abstract: Objective: to describe the use of services by children and adolescents with special health care needs (CSHCN) and its implications in the constitution of the healthcare network (HN). **Methods:** qualitative research carried out through interviews mediated by the Speaking-Map with 17 families of CSHCN in the first semester of 2019. The settings were the pediatric first-aid post and the pediatric admission unit of a teaching hospital. Data were submitted to inductive thematic analysis. **Results:** the themes that originated from the analysis were: Path taken to the articulation of the healthcare network of CSHCN and Challenges in the articulation of the healthcare network of CSHCN. The themes pointed out the discontinuity of the healthcare network of CSHCN. **Conclusion:** families of CSHCN do not have access to a consolidated reference and counter-reference flow at the healthcare networks and face constant peregrinations throughout the network searching for healthcare services.

Descriptors: Children; Adolescents; Chronic disease; Health care networks; Pediatric nursing

Resumo: Objetivo: descrever como ocorre a utilização dos serviços por crianças e adolescentes com necessidades especiais de saúde (CRIANES) e as implicações destes na constituição da rede de atenção à saúde (RAS). **Método:** pesquisa qualitativa desenvolvida por meio de entrevistas mediadas pelo Mapa Falante com 17 familiares de CRIANES no primeiro semestre de 2019. Os cenários foram o Pronto-Socorro Pediátrico e a Unidade de Internação Pediátrica de um hospital de ensino. Os dados foram submetidos à análise temática indutiva. **Resultados:** os temas oriundos da análise foram: Caminho percorrido para a articulação da rede de atenção à saúde de CRIANES e Desafios para a articulação da rede de atenção à saúde de CRIANES. Os temas apontaram a descontinuidade da rede de atenção à saúde de CRIANES.

I Nurse graduated from Federal University of Santa Maria. Santa Maria, RS, Brazil. E-mail: hentiele@gmail.com, Orcid: <https://orcid.org/0000-0002-6591-8387>

II Nursing Student, Federal University of Santa Maria. Santa Maria, RS, Brazil. E-mail: diuliacoliveira@gmail.com, Orcid: <https://orcid.org/0000-0003-2768-6148>

III Nurse, MSc in Nursing, Doctoral Student in Nursing at Federal University of Santa Maria. Santa Maria, RS, Brazil. E-mail: carensbertoldo@gmail.com, Orcid: <https://orcid.org/0000-0002-0199-134X>

IV Nurse, Professor at the graduation and postgraduation Nursing course, PhD in Nursing and Postdoctoral in Nursing in Public Health, Federal University of Santa Maria. Santa Maria, RS, Brazil. E-mail: eliane.neves@ufsm.br, Orcid: <https://orcid.org/0000-0002-1559-9533>

Conclusão: as famílias não possuem um fluxo de referência e contrarreferência consolidado nas RAS e enfrentam constantes peregrinações pela rede na procura pelos serviços de saúde.

Descritores: Crianças; Adolescentes; Doença crônica; Redes de atenção à saúde; Enfermagem pediátrica

Resumen: Objetivo: describir como ocurre la utilización de los servicios por niños y adolescentes con necesidades especiales de atención en salud (NANEAS) y sus implicaciones en la constitución de la red de atención de salud (RAS).

Método: investigación cualitativa desarrollada por medio de entrevistas mediadas por el Mapa Hablante con 17 familiares de NANEAS en el primer semestre de 2019. Los escenarios fueron el puesto de primeros auxilios pediátrico y la unidad de internación pediátrica de un hospital de enseñanza. Los datos fueron sometidos a un análisis temático inductivo.

Resultados: los temas oriundos del análisis fueron: Camino recorrido para la articulación de la red de atención de salud de NANEAS y Desafíos para la articulación de la red de atención de salud de NANEAS. Los temas señalaron la discontinuidad de la red de atención de salud de NANEAS. **Conclusión:** las familias no tienen un flujo de referencia y contrarreferencia consolidado en las RAS y enfrentan constantes peregrinaciones por la red en la busca por los servicios de salud.

Descriptor: Niños; Adolescentes; Enfermedad crónica; Redes de atención de salud; Enfermería pediátrica

Introduction

Children with special health care needs (CSHCN) are children and adolescents that are at a greater risk of presenting a chronic condition that requires specific assistance, often continuous and complex, temporary or permanent, at healthcare facilities.¹ CSHCN require singular care to support their healthcare demands, which include hospital, primary, and home care, requiring communication between these services in order to ensure continuity of care.²

CSHCN are classified according to healthcare demands and are divided into 4 groups: development, technological, medical, and modified habitual. The first includes children and adolescents with neuromuscular disorders that require psychomotor and social rehabilitation. The second, the ones that need colostomy bags, tracheostomy tubes, hemodialysis, among others. The third, the ones that take medication, for example, anticonvulsants. Lastly, the modified habitual group includes children and adolescents that need modifications in their habitual way of performing common daily tasks when compared to another child of the same age or need assistance to execute an activity.³

In Brazil, there is no official epidemiological data regarding CSHCN among the overall population, and no specific public policies for this group, which evidence their invisibility.⁴ A study

carried out at three Brazilian towns found a 27% prevalence of CSHCN with the *Children with Special Health Care Needs Screener*® tool (CSHCN Screener).⁵ Although legislation is still incipient regarding this group, there is the National Policy for Full Attention to Children's Health (hereby called PNAISC) that determines, as a strategy for its implementation, the use of the Singular Therapeutic Plan (STP), the Home Care Service (HCS) and dehospitalization programs aiming the continuity of assistance at the primary healthcare and the constitution of the healthcare network (HN).⁶

The reference and counter-reference system is inherent to the HN, which is constituted from organizational principles of actions and healthcare services of different technological densities, that are integrated through technical, logistical, and management support systems, and aim to overcome healthcare fragmentation. Therefore, they strive to perfect the political-institutional functioning of the Brazilian unified health system (SUS) in order to guarantee the set of actions and services that the user needs, with effectiveness and safety.⁷

Reference is characterized by the referral of basic health units (BHU) to higher technology levels (medium and high). Counter-reference figures as the return of the user from medium or high technology level to primary health care (PHC).⁸ Thus, the HN constitutes a set of services integrated into healthcare in a way that allows people to receive continuous preventive and healing services according to their needs, over time, and through different levels of healthcare.

The necessity perceived by the user, according to their health situation, makes them use healthcare services. That includes direct (appointments and hospitalizations) and indirect (preventive and diagnostic tests) contact with services.⁹ A study conducted with this group of children and adolescents pointed out the fragility and disarray of the HN, showing a centralization of specialized services, characterizing a use focused on specialty and on the biomedical model, in which the access is sought by family members and caregivers.²

Therefore, it is important to investigate how the CSHCN healthcare network is constituted, in order to identify weak spots and potential knots in this net. Hence, this study aimed at answering the following research question: how does the use of services by CSHCN occur and what are its implications to the constitution of these children and adolescents' HN and their families? As objectives, it is intended to describe how the user of services by CSHCN occurs and its implications in the constitution of HN.

Methods

This was a qualitative, exploratory descriptive study carried out at the pediatric first-aid post and the admission unit of a teaching hospital, which is a reference hospital in tertiary care for the population of 45 towns of the central-western region of Rio Grande do Sul. The pediatric first-aid post includes six beds, of which one is a quarantine bed, and attends the referral demand, therefore not working as an open-door hospital, and it receives referral from all the covered region. The pediatric admission unit has 19 beds including surgical and clinical specialties. Both units receive patients from age 29 days to 15 years.

Data were collected through semi-structured interviews with 17 caregiver Family members of CSHCN, mediated by the Speaking-Map technique,¹⁰ from March to June 2019. The closure of data collection followed the criterium of reaching enough theoretical density to accomplish de goals of the study, assessed according to pre-analysis of the results.¹¹

The inclusion criteria were age, given that, according to the child and adolescent statute, a person is considered a child until the age of 12, and an adolescent from the age 12 to 18.¹² For the definition of Family members, all the individuals that have some kind of emotional bond with one another, regardless of consanguinity, following the principle that family members are the ones that the members of the family say they are,¹³ and caregivers are the ones that provide home care for the children and adolescents.

In addition, the selection of participants among the patients aged from 0 to 18 admitted to the unity, was carried out through the CSHCN screening tool, translated and adapted to Brazilian Portuguese, called *Children with Special Health Care Needs Screener*® (CSHCN Screener).¹ Family members under 18 years old were excluded from the research.

This screening tool consists of five structured questions that must be answered by the ones who provide care to the children and adolescents, whether or not they are family members, allowing to identify and evaluate the healthcare demands of each child and adolescent according to three domains: dependence on medication prescribed for a certain clinical condition, use of healthcare services above the considered usual or standard rate, and the presence of functional limitations.¹⁴

The screening tool was applied to family members of children and adolescents. When answering “yes” to at least one of the questions, the child or adolescent was defined as CSHCN, and the family member became eligible for participating in the study. After the selection, participants were led to a private room where interviews took place. The interviews lasted 30 minutes on average and were carried out by the main researcher and recorded on sound.

The semi-structured interviews consist of a script with closed questions, usually for identification or classification, but mainly of open questions allowing the person interviewed to speak more freely about the proposed topic. The interview script was built in such a way as to achieve the proposed goals. The construction of the speaking-map aims to graphically represent a problematized situation of the community reality, which must be constructed by people who are interested in knowing and solving problems encountered.¹⁰

The technique was developed at the end of the semi-structured interview. Family members were invited to draw a speaking-map with the following leading question: “Demonstrate to me through the drawing, the path you take from your home to have healthcare assistance for [children/adolescent’s name]”. This technique allowed family members to express themselves orally as well as through drawing how the referral and flow of the HN occurred for these children.

Interviews were fully transcribed and submitted to inductive thematic analysis.¹⁵ It is worth highlighting that there was no analysis of the drawings by the researchers because in this technique, which is part of the Sensitive Creative Method, the participant describes and explains their own drawing and why they made it. Their wording regarding the artistic work created is analyzed as an inherent element of the corpus of the interview.¹⁰

The inductive thematic analysis is developed within six stages of implementation, which are: familiarity with the data, which consists of transcribing and rereading the interviews; generation of codes, which performs a systematic codification of the characteristics of data in common; search for topics, based on the combination of important results in order to group and form potential topics; review of topics, which is characterized as a verification of the relationship between topics and data and generation of the thematic for the analysis; definition of nomenclature of the topics and, lastly, report preparation, which is defined as a last opportunity for the analysis of the extracted data.¹⁴ This step brings up the analysis of the research question, and it is when the interpretations predicted on the theoretical framework are conducted, allowing the final draft of an academic report.

This study followed all the ethical determinations for studies with human beings, according to Resolutions nº 466 from 2012, nº 510 from 2016, and nº 580 from 2018, and it was approved by the local ethics and research committee under the number 3.109.233 and Certification of Presentation to Ethical Appreciation: 05181118.8.0000.5346 from January 09, 2019. In order to ensure anonymity, the letter E was adopted as a code for “interview”, presented in ascending order (E1, E2, successively). In addition, “SPEAKING-MAP” was also used, followed by the code of each interview, as in the example: “SPEAKING-MAP, I1, I2” and so on.

Results

Among the 17 caregiver family members interviewed, 11 male and 6 female CSHCN were identified. Table 1 shows the characterization of the CSHCN.

Table 1 – Characterization of the CSHCN according to diagnostics, specialties and services, age and healthcare demands. Santa Maria - RS, 2020.

| Number of respondents | Diagnostics | Specialties and Services* | Age | Healthcare Demands** |
|-----------------------|-----------------------------|--|---|---|
| 01 | Reflux | Psychology, Phonoaudiology, Gastroenterology, Hospital. | 2 years 4 months old | Medical, Technological, Modified Habitual. |
| 01 | Atopic Dermatitis | Dermatology, Psychology, Hospital. | 8 years | Medical, Habitual Modificado. |
| 01 | Microcephaly | Pediatrics, Neurology, APAE (Association of Parents and Friends of Exceptional Children), Health Post, Hospital. | 7 years old | Medical, Technological, Modified Habitual, Development. |
| 01 | Rare disease (Interrogated) | Physical Therapy, Neurology, Psicologia, Health Post in town, Hospital. | 4 months old | Medical, Technological, Modified Habitual. |
| 02 | Down Syndrome | First-aid Post, Hospital, Health Post in town / Phonoaudiology, Physical Therapy, Pneumology, Occupational Therapy, APAE, Hospital, Popular Pharmacy in town. | 2 months old / 1 year 5 months old | Medical, Modified Habitual. |
| 01 | Sickle Cell Anemia | Hematology, Popular Pharmacy in town, Health Post in town, Hospital. | 9 years old | Medical, Modified Habitual. |
| 01 | Guillain Barré Syndrome | Pediatrics, Physical Therapy, Health Post in town, Hospital. | 2 years old | Medical, Modified Habitual. |
| 03 | Cerebral Palsy | Physical Therapy, Phonoaudiology, Pneumology, ICU, Pharmacy in town, Hospital / Traumatology, Occupational Therapy, Psychology, Physical Therapy, Nutrition, Pneumology, Pediatrics, Neurology, Rheumatology, Psychiatrist, APAE, Hospital, First-aid, Hospital/Pediatrics, First-aid, Hospital. | 6 years old / 6 years old / 6 years old | Medical, Technological, Modified Habitual, Development. |
| 01 | Chronic Kidney Disease | Nephrology, Psychology, Hospital. | 13 years old | Medical, Technological, Modified Habitual. |
| 01 | Colostomy | First-aid, Hospital, Health Post in town. | 11 years old | Technological, Modified Habitual. |
| 01 | Deletion of Chromosome | Nephrology, Otolaryngology, Endocrinology, Pneumology, | 13 years old | Medical, Technological, Modified Habitual. |

| | | | | |
|----|--------------------|---|--------------|--|
| | 16 | Gastroenterology, Phonoaudiology, Physical Therapy, Hospital. | | |
| 01 | Hepatomegaly | Cardiology, First-aid, Hospital. | 7 years old | Medical, Modified Habitual. |
| 01 | Leukemia | Neurology, Hematology, Pediatrics, Hospital. | 11 years old | Medical, Modified Habitual. |
| 01 | Mental Retardation | Neurology, Psychology, Hospital. | 8 years old | Medical, Modified Habitual, Development. |

* As reported by caregiver family members in the interview.

**According to screening tool *Screener*®

CSHCN are classified according to healthcare demand and divided into four groups: development, technological, medical, and modified habitual. Considering the characterization of the participants, despite the diagnosis, they all exhibited healthcare demands that classified them as CSHCN. The medical and habitual modified demands were the most common, although it is important to highlight that some of these children and adolescents have all of the healthcare demands in their daily life. During data analysis, two thematic categories were listed: “Path taken to the articulation of the healthcare network of CSHCN” and “Challenges in the articulation of the healthcare network of CSHCN” which will be presented below.

Path taken to the articulation of the healthcare network of CSHCN

The caregiver family members of the participants of the study go through different services in seek of assistance for their children.

The pediatrician referred us to Passo Fundo [...] since there was no hospital bed for us there, we ended up coming to Santa Maria. (I4)

I'm from Alegrete, very far away. When I got here and went to the hospital, because I took her to the health post in Alegrete, I tried to book an appointment twice when they found out that she had kidney problems. (I9)

She actually had medical follow-up in every specialty, she comes to the pediatrician, neurologist, pneumologist, rheumatologist, now she started psychiatry and I don't know if she will need some more, she has lots of follow-ups [laughs]. (I11)

We looked for a dermatologist, private practice, he referred us to the hospital here, I looked for help in my town, at the healthcare post, they referred me to the health secretary and we booked an appointment here at the hospital and came back here for the treatment. (I2)

It was identified that the path taken in the seek for healthcare goes through various obstacles, and eventually healthcare services are not problem-solving nor enough to fulfill these children and adolescents' demands. Thus, caregiver family members are re-referred many times to the locations of these services, sometimes traveling from one town to another, trying to guarantee the assistance they need.

Furthermore, during the creation of the speaking-map, it was possible to identify the path taken by these family members of CSHCN on the seek for assistance.

[...] we leave home and go to the phonoaudiologist, when he feels bad we go to the hospital back in town, then they [health professionals] see if he has to come here [hospital] or not; from the times we go to the health post, as the time we went to get the referral, to go to the pediatrician, to be referred to the gastrologist as well, the times we come to the health post here too via health secretary to get food referral, and then for the appointments we come to the hospital, and go back, we did this lots of times since he was born, almost every month we have some kind of follow-up to come back here, sometimes an exam, sometimes a follow-up appointment. (SPEAKING-MAP, I1)

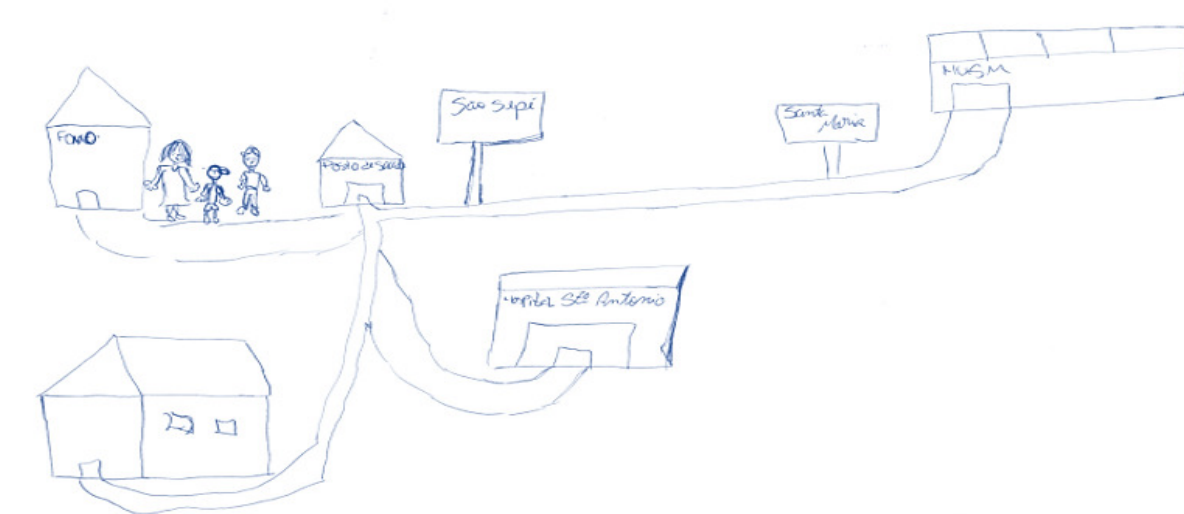


Figure 1 – Speaking-map created by E1.

During the creation of the speaking-map, the long path that caregiver family members of CSHCN have to take in seek for assistance and resources to fulfill the demands of CSHCN become evident. They travel between primary, secondary, and tertiary care services of the public health system, besides resorting to private services whenever necessary. I2 describes a similar situation in their speaking-map.

[...] we would go to the health post, from there they referred us to the health secretary, then to the hospital, and then it was the path we took the most, until they referred me to the hospital here, that's about how it happens [...].
(SPEAKING-MAP, I2)

**Figure 2** – Speaking-map created by E2.

Hence, it was found that the respondent sought assistance at the PHC, went through the health secretary in her town in order to get the referral to the high technology service to have medical assistance for the child with special health care needs. I6 also illustrates, through the speaking-map, the path she had to take to get to the hospital.

[...] *I'll draw my house here, we go through the first-aid post, me and my wife don't like it there because of what happened, then I'll put an X here [...] here [at the hospital] is further from home, but we prefer to come here, he was really sick.* (SPEAKING-MAP, I6)



Figure 3 – Speaking-map created by E6.

Although some of the paths were more straightforward than others, overall there were disturbances and significant routine changes in order to get to the services that would fulfill the demands of the CSHCN in question. According to the statements, it becomes evident that there is a need that most caregiver family members had to resort to private services initially, to only then be referred to higher technology services to get a medical follow-up.

It was noticed that families had a preference for the tertiary healthcare service, describing it as fast, resolute, welcoming, and that they felt safe with the assistance offered by the hospital services, besides finding it facilitated the continuity of care.

The assistance here [hospital] is excellent, they're taking good care of him as much as of me, since I sometimes feel down too, I feel that the professionals are always with me. (I3)

The assistance from the doctors and nurses, I can only be thankful to everyone, I felt very welcome since the first time I came here [hospital] [...] because we know that there is usually a waiting line for dermatology, and it was actually kind of fast. (I2)

It is wonderful here [hospital], the nurses are very nice, they really like her and are really, really nice to her, I was really happy. This place is one hundred percent nice, they're really kind and loving with the children, it is wonderful. (I9)

The reports demonstrate that some caregiver family members do not seek assistance at the primary healthcare service, underlining that it is not resolute and they do not have bonds with the professionals from this service.

At the health post, it may take time to have assistance. For example, the referral for an exam, or something like that. I know here is really fast, when you least expect it they are already taking tests that we didn't even know he had to have. (I3)

We get there and he isn't used to them, he doesn't want to stay in the room with them. (I1)

In my town, they went as far as to tell me they didn't know what to do with him. There, everybody who has a special child complains about it, that there is no assistance, that they don't know how to deal with it, especially my child, who is one of the most severe cases. (I17)

Furthermore, it is highlighted that they seek alternative sources of help to guarantee continuity of care for the CSHCN, through complementary information about diagnostics, help, and emotional support during tough times and the seek for private services, for medical reasons or because of the healthcare services.

Over time, we talk to other people who have the same problem [...] the most difficult thing is to get the medicine, it is an expensive medicine [...] the dermatology medications I think it would be nice if we had more support from the government, because it's a really expensive treatment. (I2)

After waiting for the scheduling, I would end up looking for private services as well [...]. I try to look for help through social media. (I1)

Medication [...] yeah, there's two of them that I have to pay for, that I couldn't get via SUS. (I10)

Physical Therapy, phonoaudiologist, occupational therapy [...] we end up having to pay for them. (I6)

With this, the persistency of the families on the seek for fulfilling the necessities of their children, even in the face of situations of tireless peregrination through health services, becomes evident.

Challenges in the articulation of the healthcare network of CSHCN

From the data collection, it was identified that despite the seek for assistance, there is a lack of assistance from the HN in caring for the families of CSHCN, thus highlighting challenges in finding a solid HN, with an appropriate flow and that provides the necessary and integral healthcare services to this public.

We have to wait for the call to make an appointment, to be called for the appointment, and then there are a few more days until this appointment. In the hospital [from the town of origin] where I live there is no pediatrician [...]. We've been waiting since January for these procedures. (I1)

We kind of went everywhere. (I1)

And now we've been waiting for the phonoaudiologist and the physical therapy via health secretary for almost a year and a half, and there is still no word. (I13)

It's really difficult, it's complicated [...] I think it lacks agility, speed, it takes too long [...] After 6 p.m., in the hospital, there is no x-ray nor hemogram, it's really difficult [...] we have to come here or wait until the next day, that's why I think it's easier to come here than to wait there. (I7)

The sickness of the child or adolescent constitutes an unexpected process to any family, and it often causes feelings such as denial or guilt, but mainly fear, pain and suffering. The peregrination of families of CSHCN through the HN results in these feelings, as evidenced by the statements.

First we feel grief, only mothers know, we never expect that, we never expect our child will demand a little more care. (I5)

Because there's nothing else you can do, you do everything [...] then, it is something that encouraged me, you know, to be a strong mother. (I3)

I do understand, I just don't accept it [...]. I'm really scared of operating rooms and anesthesia [...] everything that is going to happen to him scares me. In the beginning you don't realize, it's a shock, you do, you cry, then you breathe and say: no, let's keep going [...]. (I4)

It has been really intense, a lot of uncertainty, the Down Syndrome is not the problem, but what comes with it, so it's basically insecurity, and all really rushed because I have two more children at home, so [...] everything [...] changed our routine completely. (I5)

Despite that, the orientation given by health professionals, especially the nurse, helped in facing peacefully this difficult period.

The girls there gave me a lot of hints, so, it was really valuable everything that we learn [...] we spend more time with the nurses, lots of suggestions of daily living, so the nurses are the ones we talk to more often, they give us all the hints we need. (I2)

So I started to do everything they suggested [...] they[nurses] are always by my side, always helping me, supporting me, always saying we have to keep our heads high and be strong [...] I feel safer, you know? With them, I feel more protected in here as well. (I3)

Hence, it is important that health professionals provide orientation to families, contemplating their care from admission to hospital discharge, strengthening the bond, promoting the autonomy of these caregiver family members, softening the fears and anguishes along the way.

Discussion

The special needs of CSHCN include complex healthcare by caregiver family members in the household. These families face constant peregrinations in seek of specialized assistance and require

a multidisciplinary healthcare network to contribute to the continuity of healthcare of CSHCN at the PHC.²

Considering the condition and nature of the healthcare demands of CSHCN, it is observed a necessity of health and social services beyond the required by any other child and usually for an indefinite duration.¹ In this context, the HN must provide resolute integral and high-quality healthcare services, and it is crucial that the PHC services are organized in order to coordinate care and be responsible for the user flow, so as to optimize the reference and counter-reference services that are needed for the follow-up of these children.¹⁵

With respect to the path, it was possible to identify that the families do not have a consolidated assistance flow at the HN, as it should be according to Ordinance nº 4.279, which establishes guidelines for its organization in the scope of the SUS.⁷ This becomes evident considering that CSHCN enter the healthcare network through other health services, usually through the private network. In addition, families report that they search for higher technology services when in seek of assistance for their children instead of primary healthcare services, which shows difficulties in accessing continuity of treatment for CSHCN after hospital discharge. They face constant peregrinations in seek of access and resolutivity of healthcare services, due to many failures in organization and structure of the healthcare networks that fail to fulfill the actual needs of the families.

It is therefore necessary to restore the coherence between the situation of the child and adolescent and the SUS, which involves the adequate implantation of the HN. The organization of the HN in integrated systems enables an effective response, with efficiency, safety, quality, and equity, to the health conditions of Brazilian people and consequently, of CSHCN.¹⁶

The absence of an effective reference and counter-reference system hinders the path of these caregiver family members, besides violating the principles of integrality and universality, as well as the rights of the users of the SUS.⁸ In this study it was noted that the primary healthcare services

need to be strengthened as a gateway to assistance for the population. There is also a need for an effective reference and counter-reference service that would enable the continuity of assistance after hospital discharge.

With regard to challenges, it is important to highlight that the situation of hospitalization, awakened due to the sickness of children, causes despair, fear, and helplessness/incapacity to family members.¹⁷ This influences the family structure, leading to physical, emotional, and social overload of caregiver mothers of CSHC.¹⁹ This study also highlighted that caregiver mothers of CSHCN present higher overload scores when the longitudinality was not effective at the PHC.¹⁸

The healthcare team must be prepared to provide support, which makes it necessary to train the professionals at the HN, as well as ensure the qualification of the communication between healthcare services and the family at the different levels of healthcare, aiming for the articulation of all the dimensions of the management of care for children and adolescents at the PHC.¹⁹ It is also important that the health professionals implement articulated actions through social media that center on the children and their families, so it can contribute to the reorganization of the family dynamics and a better facing of the situation by the child.²⁰

The results demonstrated that caregiver family members need to search for different sources for help in order to provide adequate care for their children, either for medicines, private health services, or specialized professionals. Such information evidences a (de)constitution of the healthcare networks, considering that they are unable to provide an articulated, quick, and effective assistance for these children, aiming the integrality of care, as set out by the PNAISC, with regards to the care for children with chronic conditions at the HC, which can be carried out through STP, HCS, and dehospitalization programs.⁶ This causes a disarticulation of the planning of actions of care at the HC, along with the discontinuity of the care for children and adolescents with chronic conditions and their families.²

It is noted that there is a lack of studies about the HC of CSHCN, as well as researches that bring up the existence of this public and their difficulties at accessing reference and counter-reference services for the treatment of these children and adolescents. The insertion of public health policies that are specific or these children and adolescents, as well as the implementation of the existing ones is crucial for the acknowledgment of CSHCN, who need a healthcare practice and singular public politics in order to fulfill their demands.

The limitations of this study include the fact that all the participants came from the same institution. It is therefore suggested the investigation of this topic with participants from other institutions, in different parts of the country, in order to understand the use of the HC services in other geographical areas.

Conclusion

The findings of this study pointed out a (de)constitution of the HC services regarding its use by CSHCN. From a dialectic perspective, this means there is a solitary constitution through peregrinations, made by caregiver family members and a (de)constitution caused by the non-implementation of actions by the government on the HC. Participants highlighted the difficulties of articulation and flow after the discharge of the CSHCN. The majority of them end up opting for private healthcare services to have access to the healthcare network more quickly and prefer to search for assistance at high technology services in cases of exacerbation of the child's condition.

It is therefore important that nursing professionals provide a moment of listening to the caregiver family members of CSHCN, recognizing, within the subjectivity of the care developed by the family, spaces of interchange of knowledge and autonomy. In this way, an educational practice can be developed from admission to hospital discharge, so these caregivers can become empowered to fulfill the demanded care of CSHCN in their household, as well as when using the HN services.

In the scope of education, the process of continuing education of health professionals can contribute to professional training through enabling de constitution of the HC, in a multidisciplinary and integral way for CSHCN. This can have an impact on reducing hospitalizations and improving the quality of life of these children and their families.

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Corresponding author

Eliane Tatsch Neves

E-mail: eliane.neves@ufsm.br

Address: Rua Padre João Bosco Penido Burnier, N° 130, apto 302. Bairro Camobi, Santa Maria, RS.

CEP: 97105-190

Authorship Contributions:

1 – Hentiele Feksa Lima

Participated on the conception or study design/research and analysis and/or interpretation of the collected data.

2 – Diúlia Calegari de Oliveira

Participated on the analysis and/or interpretation of the collected data, review and scientific standards.

Autor 3 – Caren da Silva Bertoldo

Participated on the conception or study design/research, analysis and/or interpretation of the collected data, final review, critical and intellectual participation on the manuscript.

4 – Eliane Tatsch Neves

Participated on the conception or study design/research, analysis and/or interpretation of the collected data, final review, critical and intellectual participation on the manuscript.

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