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Health care network for children with zika virus from the perspective of professionals

Rede de atenção à saúde de crianças com zika vírus na perspectiva de profissionais

Red de atención a la salud para niños con virus zika desde la perspectiva de profesionales

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ABSTRACT

Objective: To know the perspective of health professionals working in specialized care regarding the assistance offered to children with Congenital Zika Virus Syndrome in the Health Care Network.

Method: Qualitative study carried out in Campo Grande-MS through semi-structured interviews, between September and October 2020, with 12 professionals working in a reference service for people with physical and intellectual disabilities. Minayo's thematic analysis and the theoretical subsidies of the care model for chronic conditions were used for interpretation.

Results: Assistance in the network is weakened by aspects related to access, monitoring and integration between different professionals/services. The potential involves the

implementation of the referral and counter-referral system, the communication/integration between these services and the training of professionals.

Final considerations: The participants perceive that assistance is influenced by the availability of trained professionals to work in a network and the optimization of access and follow-up at different points of care.

Descriptors: Zika virus. Children. Chronic disease. Continuity of patient care.

RESUMO

Objetivo: Conhecer a perspectiva dos profissionais de saúde atuantes na atenção especializada acerca da assistência ofertada às crianças com Síndrome Congênita do Zika vírus na Rede de Atenção à Saúde.

Método: Estudo qualitativo realizado em Campo Grande-MS por meio de entrevista semiestruturada, entre setembro e outubro de 2020, com 12 profissionais atuantes em um serviço de referência para pessoas com deficiência física e intelectual. Utilizou-se a análise temática de Minayo e os subsídios teóricos do modelo de atenção às condições crônicas para interpretação.

Resultados: A assistência na rede é fragilizada por aspectos relacionados ao acesso, acompanhamento e integração entre os diferentes profissionais/serviços. As potencialidades envolvem a efetivação do sistema de referência e contrarreferência, a comunicação/integração entre esses serviços e a capacitação dos profissionais.

Considerações finais: Os participantes percebem que a assistência é influenciada pela disponibilidade de profissionais capacitados para atuar em rede e a otimização do acesso e seguimento nos diferentes pontos de atenção.

Descritores: Zika virus. Criança. Doença crônica. Continuidade da assistência ao paciente.

RESUMEN

Objetivo: Conocer la perspectiva de los profesionales de la salud que actúan en la atención especializada acerca de la atención que se ofrece a los niños con Síndrome Congénito del Virus Zika en la Red de Atención de Salud.

Método: Estudio cualitativo realizado en Campo Grande-MS a través de entrevistas semiestructuradas, entre septiembre y octubre de 2020, con 12 profesionales que actúan en un servicio de referencia para personas con discapacidad física e intelectual. Para la interpretación se utilizó el análisis temático de Minayo y los subsidios teóricos del modelo de atención a las condiciones crónicas.

Resultados: La asistencia en la red se ve debilitada por aspectos relacionados con el acceso, seguimiento e integración entre diferentes profesionales/servicios. El potencial pasa por la implementación del sistema de referencia y contrarreferencia, la comunicación/integración entre estos servicios y la formación de profesionales.

Consideraciones finales: Los participantes perciben que la asistencia es influenciada por la disponibilidad de profesionales capacitados para trabajar en red y la optimización del acceso y seguimiento en los diferentes puntos de atención.

Descriptor: Virus zika. Niño. Enfermedad crónica. Continuidad de la atención al paciente.

INTRODUCTION

Children with congenital Zika Virus Syndrome (CZS) may present numerous neurological manifestations that go beyond microcephaly, with varying levels of severity, conditions and health needs⁽¹⁾. Therefore, they have frequent contact with different health care services. On a national level, in 2019, 3,474 confirmed cases of microcephaly related to the

aforementioned syndrome and other infectious etiologies were recorded. Of these cases, 56.9% occurred in the Northeast region and 7.7% in the Central-West region, with 71 cases reported in Mato Grosso do Sul with suspicion or diagnosis of congenital anomaly⁽²⁾ Given this epidemiological scenario, the Ministry of Health has issued recommendations for surveillance actions aimed at this population in Brazil, with emphasis on early diagnosis and intervention⁽³⁾.

The Unified Health System (SUS) has consolidated itself based on the integration of services, from the perspective of comprehensiveness and continuity of care and intersector action for health promotion⁽⁴⁾. The Health Care Network (RAS) aims to provide offer quality care in a continuous, comprehensive and humanized way, through the coordination between health actions and services and the construction of horizontal relationships between the different points of care, with Primary Health Care (APS) as an entry point to the health system⁽⁵⁾.

For children with CZS, the availability of RAS services is a necessary, but not sufficient, condition to ensure access. The system also needs to have the capacity to facilitate entry, encourage continuity of assistance and coordinate intersector activity⁽⁴⁾. Furthermore, comprehensive care for children with CZS in the RAS requires greater coordination between professionals from different points of care, as well as professionals trained to assist this population.

Regarding the gaps in assistance to these children and families, it is worth mentioning the absence of a consistent network capable of enabling a defined flow for care for this population in the same physical space, in a multidisciplinary and longitudinal manner, valuing the bond, active and humanized listening, as well as the qualification of health professionals⁽⁶⁾. The few and sporadic actions already carried out at different points of the RAS for similar target populations did not guarantee resolution and continuity to the unique and ongoing demands of these children and their families⁽⁷⁾.

New ways of organizing services that include investments in the management and management of chronic conditions, focusing on promoting and maintaining the health of children with CZS, regardless of their geographic location, are necessary in order to reduce avoidable premature deaths, disabilities and injuries⁽⁸⁾. The commitment of the interdisciplinary team and RAS health managers to the continuity of care for these children is essential for the implementation and operationalization of existing policies and the recovery of the expanded concept of the health-disease process⁽⁹⁾.

In view of the above, from the perspective of continuity of actions across different points of the RAS, this study can support nursing and health care in planning strategic care actions aimed at promoting the quality of life of children with the syndrome and their families. From an academic perspective, it can be seen that in Brazil insufficient progress was made in research into care for children with CZS, especially with regard to aspects related to continuity of care in the context of RAS. Therefore, the following question was proposed: how has the assistance for children with SCZ been in the health care network? Therefore, this study aimed to gain insight on the perspective of health professionals from specialized care services regarding the assistance offered to children with Congenital Zika Virus Syndrome in the Health Care Network.

METHOD

Qualitative study with an exploratory-descriptive approach carried out in the city of Campo Grande, capital of the state of Mato Grosso do Sul, located in the Central-West region of Brazil. The criteria established in the Consolidated Criteria For Reporting Qualitative Research (COREQ) were used in the elaboration of the research report.

The Campo Grande macro-region is made up of 34 municipalities and a total population of 1,364,668 inhabitants. The study was carried out in one of the six rehabilitation services of the Care Network for People with Disabilities in the Macroregion, within the scope of the Unified Health System.

The aforementioned service was selected because it is the largest in the state of Mato Grosso and because it provides undergraduate and postgraduate internships in the health area (multidisciplinary residency in rehabilitation). As the service is a reference for people with physical and intellectual disabilities, many cases of children with microcephaly, including those affected by SCZ, were recorded there. At the time the study was carried out, the service had 13 doctors, a social worker, 23 physiotherapists, 14 speech therapists, 29 psychologists, 12 occupational therapists, four nurses and three nutritionists.

The invitation to participate in the study was made personally by the main researcher, to all eligible professionals, with support from the coordinator. On that occasion, a professional expressed his refusal to participate.

All participants were professionals with higher education, who recorded the care provided to children with SCZ and their families in medical records. Professionals on leave due to the contingency planning adopted by the institution in the face of the pandemic caused

by the coronavirus and those who, after several attempts, claimed unavailability in their schedules to carry out the interview were not included.

Data were collected in September and October 2020. Initially, the main researcher asked the service coordinator for the medical records of all children with SCZ seen in the previous year (2021), in order to identify the health professionals who recorded the care provided to these children. Analysis of the selected 14 medical records showed that of the 30 eligible professionals, half of them were on leave. The 15 who were active during the data collection period were a doctor, a nurse, a nutritionist, a social worker, two psychologists, five physiotherapists and four occupational therapists.

The individual semi-structured interviews were carried out on the same day, in a private room in the health service. All interviews were carried out by the first author (nurse, master's student in nursing with experience in conducting interviews, due to her participation in studies developed by members of the research group to which she is linked). She did not have any type of relationship with the professionals of the health service.

Despite the pandemic period, all interviews were in-person, previously scheduled, audio-recorded after participants' consent and lasted an average of 60 minutes. The interviews were guided by an interview guide prepared specifically for this study, consisting of questions related to the characterization of the participants and with the following guiding question: tell me how you perceive the assistance offered to children with CZS in the context of the RAS?

When necessary, some support questions were also used, including the following dimensions: the path taken by the family in the search for care; the assistance offered at different entry points in the RAS; communication between health services/professionals at different entry points in the RAS; and actions that favor continuity of care in the RAS. Both the guiding question and the supporting questions were discussed and improved in the research group responsible for conducting the study. Therefore, the researchers felt it was unnecessary to carry out the pilot test.

Data collection ended when all potential participants had already been approached and the objective of the study had been achieved. The two main researchers (master's student and supervisor) consensually decided not to continue insisting on the participation of three professionals (a nurse, a physiotherapist and a doctor) who were unavailable to schedule the interview, understanding that they did not want to participate, despite having been offered several opportunities.

For data processing and analysis, all interviews were transcribed in full, preferably on the same day as they were carried out and were subsequently subjected to thematic content

analysis⁽¹⁰⁾. In the pre-analysis stage, floating reading of the interviews was carried out for the identification of initial impressions. Therefore, the material was explored through a thorough reading of the interviews, data coding and grouping into units of meaning⁽¹⁰⁾.

At first, 22 codes were identified, which, when grouped together, gave rise to the following units: difficulties in access; communication between health professionals; integration between RAS services; PHC's role in providing assistance; family resistance to discharge from the specialized service; reference and counter-reference; the role of the manager in managing care; family/professional knowledge about how the RAS works; and professional training for network care. In the stage of processing of results, after categorization and grouping of the codes, two thematic categories emerged that were interpreted and discussed based on the theoretical subsidies of the chronic care model (MACC)⁽¹¹⁾ and inferences were made regarding the findings.

The transcribed interviews were not submitted to the participants for content validation, as due to the pandemic and the absence of several co-workers, the professionals were overwhelmed and did not show interest in carrying out such validation when approached. However, the results obtained were subjected to evaluation by another member of the research group to check for possible misinterpretations. No such mistakes were identified.

The development of the study observed the ethical principles of Resolution No 466/2012 and was approved by the Ethics Committee of the signatory institution (CAAE No 30718620.2.0000.0021 and Protocol No 4.133.629). All participants signed the Free and Informed Consent Form. To preserve their anonymity, when presenting the results, excerpts of their speeches are identified with the letter "P" followed by a number corresponding to the chronological order in which the interviews were carried out.

RESULTS

The 12 study participants were aged 26-46 years (average of 35.6 years), 11 were female, four physiotherapists, four occupational therapists, two psychologists, one social worker and one nutritionist. The length of professional education ranged between three and 18 years (average of 11.6 years), with 10 stating that they had one or more specializations. As for the length of time working in the service, it ranged from 11 months to 9 years (average of 5.3 years). Below, the two thematic categories that emerged from the analysis of the interviews:

Weaknesses in assistance to children with Congenital Zika Virus Syndrome in the Health Care Network

Among the difficulties encountered in offering continuous assistance in the RAS, participants stressed that discontinuity of care is a reflection of the lack of integration between the different services that make up the support and care network for children with CZS and their families:

If anyone says that there is coordination between services, it is a lie; It's really bad, it seems like everyone only looks out for their own interests. It's the same thing with education and health, they don't seem to be connected. (P4)

[...] why do I often believe that the SUS does not work? Because the whole system does not work, I think that sometimes things fail because of this, I see it as if they've been kicking the can down the road for years, and no one solves the problem. (P6)

The referral of children with CZS after birth for admission to reference services, with emphasis on the lack of registration in the regulatory system, was also highlighted:

[...] It also seems to me that even Zika virus patients left the. (name of the hospital); at that hospital they provide the referrals and tell the patients to come here to the Association of Parents and Friends of the Handicapped (APAE). and when they arrive here, we realize that the registration was not made, there is no order, there is nothing, only the doctor's orders that are in the hand of the child's mother, but nothing was entered into the system, and if it is not in the system, we cannot provide assistance; the child's mother will have to return to the clinic, make a new request, wait for the National Regulation System (Sisreg) to authorize the service so that she can return here; these are failures that could be avoided, the Network is full of problems [...]. (P5)

This lack of integration in meeting continuous demands at the different RAS points was also ratified by health professionals, through situations that characterize the absence of primary health care.

For example, a child with diarrhea or dehydration arrives, and I have no support here in the APAE. There have been many occasions when I picked up a fainting child, sent him/her to the pediatrician, and the child needed a blood transfusion or hydration. We have the support of doctors here, because sometimes this support does not exist at the health care center. (P9)

A mother came here with a child who had many sequelae, and what impressed us most is that she always said that next to her house there was land infested with dengue mosquitoes, and with all this concern about prevention, why doesn't anyone go there to check? If the prevention service worked, this should happen. (P11)

The discontinuity in the assistance provided in the health care network was also perceived as having an impact on the way managers operationalized services at the different RAS points:

In the health Network, I think what counts a lot is the role of the manager, we understand that professionals are important, recognize this and have these health professionals in the Network to provide a service that is fundamental and crucial for the structure of the Unified Health System. There are many interesting policies, but these policies alone, lead nowhere. It is necessary to have a well-designed, structured management at all levels, you cannot just think about that center, that unit, because the unit alone will not be able to assist everyone; a technical view of the subject is necessary to make specific decisions. (P1)

Even when the children's needs were met, the families resisted accepting discharge from the specialized service and/or continuity of care at other RAS service points.

The service is very poor. For example, in the network, families can receive care from a physiotherapist, but not from an Occupational Therapist (OT), they cannot find a psychologist, and sometimes there is no doctor to assist them. And here you have it all. The families find it hard to accept that at a certain point their child no longer needs care here, because of the doctors who can easily schedule appointments here, but elsewhere, people say they have a lot of difficulty getting care [...] (P3)

It's complicated when you have to discharge a patient. You have a lot of work to do to convince mothers, "Ah, he will be left without a doctor there and I don't want this, he won't discharge my son, my son will grow old here, he will stay here". But there is nothing more to be done for that child when he reaches a certain level and the syndrome has already stabilized. Then they need to look for another institution, another place [...]. (P7)

[...] the families think that professionals outside the specialized service are not qualified to care for their children affected by this syndrome. And they also say: "the person helped us, but it was no use, they don't know, they don't understand, you here know more than those outside". Sometimes families don't want care elsewhere, they want our care, out of fear, insecurity (P9)

The families referred to the punctual and momentary type of care offered in the RAS, marked by poor welcoming and fragmentation in the assistance provided:

Within the SUS service network, people complain about lack of respect, affection, feeling for others, caring, understanding the need [...] there has to be a beginning, a middle and an end, there is still a lot of that missing, for everyone to see things this way, I think there is a huge lack of that in the RAS. (P5)

Usually, when a child is taken to the network or seeks another basic care service, even in the psychology sector there is no proper welcoming. It's because the process is sometimes very fast and there is no maintenance care [...]. (P10)

I think that in the SUS Network, the care is directed to momentary needs, but this should be a continuous process; In the beginning there was a lot of talk about the Zika virus, microcephaly, and now does anyone talk about microcephaly? There is no more fear, no one talks about and now is anyone still talking about microcephaly? People are no longer afraid, no one talks about it, it's as if it no longer exists, as if the Zika virus had already come, passed, gone, ended, and the door has closed; you understand? [...].(P5)

This resistance was justified by a reality marked by long waiting lines to obtain specialized assistance:

Important appointments and exams take a long time. This has to be overcome, the waiting times are very long, and when they occur, it will no longer make any sense, because that phase of the child's development will have already passed. [...]. (P1)

The public health system is slow. I know [...] A mother told me that she waited a year and a half for an appointment with a neurologist, at a critical stage in her child's development, and every day makes a difference for this child, she is getting further and further away from his peers [...]. (P11)

I was told, however, that this delay may be related to the lack of training of the professional responsible for entering data about care to patients on the regulatory system:

The doctor entered an International Disease Code (ICD) that is not compatible, so the system refused. And which RAS and health unit professional will inform the child's mother about this? Nobody! I have seen several patients who had been refused and the mothers didn't know, no one knew, they will have to return to the unit and re-enter the data [...]. (P5)

Likewise, the delay in meeting the demands of children with CZS and their families is a weakness related to the limited knowledge of the population and health professionals about the organization and functioning of the RAS.

I think the population doesn't understand how the healthcare system works, many people don't understand that the health unit carries out this process, this integration between other specialized services. I think that this is not clear to the population or to many health professionals. They still don't have this reference, and the program was created to make it easier, to shorten this distance. Because the health unit is located in the neighborhood of the users, the health agents visit that location, they know the neighborhood and the needs of the users. I think that due to this delay, and because people have to wait in a long line, all care services end up being harmed by this flow. (P10)

The reports presented in this category demonstrated the weaknesses related to access, monitoring and integration of care between the different points of the RAS in the care of children with CZS and their families. In short, the continuity of care was marked by limitations in the organization and functioning of the network to support the demands of this public, and by the way in which professionals and the population understood the care offered.

Strategies to improve the flow of care for children with Congenital Zika Virus Syndrome in the Health Care Network

In order to meet the needs of children with CZV syndrome, particularly through specialized care, participants demonstrated how the flow of referrals to these services occurs in the context of the RAS:

Referral to the Specialized Rehabilitation Center can be made by any Primary Care professional. This referral is much faster if it is made to the health unit close to the person's home and if the professional has such knowledge, is aware that care is available there. This shortens the flow. (P11)

In addition to specialized care, given the demands for necessary long-term care, some professionals valued the role of PHC in preventing health problems and promoting health, as well as providing secondary care in the face of complications:

I think the specialized service is extremely important, but it is not more important than the prevention service. So, if we have efficient prenatal care, everything that involves prevention, it is s better because then there will be less need for specialized services. (P11)

Mothers report that they can make appointments at the health center, and that doctors there are able to provide support for the children, such as vaccinations and routine exams. When children have, for example, a seizure, and are taken to emergency care, they are also assisted and stabilized. But the mothers claim that the process is time-consuming, that the children need to stay in the units for a long time, but in the end they receive proper care. (P1)

The participants recognized the importance and need for integration/communication between different points in the network to guarantee continuity of care.

I think that the SUS Network has to be interconnected, and the work of each member has to be connected to that of the others; Many times we cannot point out or criticize what happens. I think the Network has to be integrated, can you imagine if the mother of a child came to the Association of Parents and Friends of the Exceptional and could contact the health unit, if we had contact with the health agent, everything would be perfect , imagine how much this family would benefit, how good it would be for this child. (P6)

It is necessary to improve communication between health professionals so that the flow of care for these patients in the RAS is effective, and patients do not get lost there, waiting a long time to obtain care, or receiving fragmented care. (P11)

The participants provided examples of the benefits of this communication between RAS services:

A new doctor at the health unit called here a few days ago because she was unable to place an order for a wheelchair, I said: "Doctor, I am available for whatever you need, International Classification of Diseases, guidance, referral, how to get to the Specialized

Rehabilitation Center, what needs to be done to bring this patient to the service” , and three days later the patient was already using a wheelchair... [...]. (P5)

And they presented strategies that could enhance communication between RAS services:

For example, we used to be assisted by institution X, but not anymore. It should have sent us the medical records, some tests that had already been carried out there; Sometimes we start a treatment that was no longer necessary for the child, because it had already been performed. (P4)

When regulating vacancies [referral], perhaps writing, detailing, I think it is important to document in detail what happened so that the next professional who will access the referral for that hospital discharge understands things better. There are many professionals involved and information ends up getting lost. (P8)

The existence of a universal medical record for these patients would make things much easier. For example here I see the basic information about what I need. When I open the system, I know that patient X is seen by the speech therapist, the occupational therapist, on Wednesdays, one professional at nine and the other at eight. I know the patient's ICD, I know the patient missed an appointment last week. That would make things easier [...]. (P11)

Regarding the continuity of care at different levels of health care, the participants said that families were advised to seek care according to the degree of complexity of the need presented and that there was counter-referral in cases of discharge from the specialized service, as well as in referral to more complex services:

We have here an outpatient rehabilitation center, so appointments are scheduled. For anything else, I advise the family to seek out the Basic Health Unit or emergency care. If the child has a fever, you won't have to wait for the next appointment [at the specialized service] for them to be medicated the next week. You will go to the Basic Health Unit, there they will check if it is possible to solve the problem there or they will refer the child to the medical care center. You have to act according to the child's symptom at that moment. (P1)

We always hold monthly meetings to inform the units about the patients who have been discharged, then we create a report with all the patients and send it to the units, because these are reference services.. Depending on where that patient lives, the report is sent to the reference unit by what we call a steering group [...] strategies are outlined that involve the integrality of the service; The service here at the Specialized Rehabilitation Center and at other points in the RAS provides the information for the patient to return to the unit, or sends the community health agent for a visit, to see what happened, and minimize the damage. (P11)

When we receive a child here who has already been cared for and is not eligible for us, we make a counter-referral with a written justification and forward it to other healthcare institutions, if it is a more serious sequelae, the patient must be referred to the philanthropic institution [name of institution], We also refer patients to the SUS network, if physiotherapy is necessary, we refer them to SUS clinics that provide this service, with counter-referral. (P12)

The participants also said that to strengthen network care for this population, the professional's attitude/behavior makes a difference:

Firstly, I understand that for the entire system to be interconnected it is necessary to have committed, knowledgeable, qualified people (professionals) who want to make things happen. I think Network work is not easy, it takes a lot of study, a lot of knowledge, a lot of strategy [...]. (P6)

Seven of them mentioned training as very important for working in a network, according to some of the statements listed below:

Training professionals for network communication. Not only in the area of health, but also in education, because caring for this child also involves education, I think that is the main thing. (P11)

It is necessary to train, invest in training... training and training! Professionals need to be trained to work in a network. (P2)

In this category, potential aspects related to the continuity of care for children with CZS in the RAS were highlighted, which involve the functioning of the referral and counter-referral system at different levels of health care and communication/integration between these services.

DISCUSSION

From the perspective of health professionals in a study, care for children with CZS in the RAS has weaknesses and potentialities. To ensure continuity of care for these children and their families in the context of the RAS, pre-established and clear care flows are necessary, consisting of coordinated care actions and with the purpose of longitudinal monitoring. The reason for this is that after diagnosis, the families must be included in a care routine that addresses the multiple needs of these children, as, in most cases, they require long-term treatments that involve a wide range of professionals and services in all levels of SUS care⁽¹²⁾.

To ensure comprehensive care, especially for people with chronic conditions, the action of users, workers and managers is an essential element⁽¹³⁾. According to professionals in the referred study, comprehensive care, as proposed in the MACC⁽¹¹⁾, could contribute to reducing the weaknesses identified, reporting that sometimes, in an attempt to provide their children with what they consider best, mothers face many challenges in accessing network services and, for this reason, they establish their own flows of care. The difficulty in accessing care network services is a reality experienced by caregivers of people at different stages of development and with different chronic conditions that have become increasingly frequent.

Studies carried out in Brazil⁽¹⁴⁻¹⁶⁾ and abroad^(13,17) highlight the paths taken and the challenges faced by caregivers in search of care.

In the case of children with CZS, the difficulty in operationalizing the flow of care may be related to insufficient knowledge about the syndrome and/or unpreparedness of services and professionals working in the RAS to meet the demands of this population⁽¹⁵⁾. A study with 19 family caregivers of children with special needs in two Brazilian municipalities highlighted that this routine is marked by travel to different points of the RAS, mainly in the search for a medical diagnosis and, subsequently, for care in the specialized service⁽¹⁶⁾, which was also highlighted in the present study. A study that aimed to identify predictors of access to support among families of children aged 0-6 years, with special health needs, in the United Kingdom, highlighted the need to improve the processes of formal identification of the demands of these children and their families, as well as addressing socioeconomic disparities and providing more accessible services, for example, coordinating support and flexible delivery of care services⁽¹⁸⁾.

In the perception of the health professionals in this study, even after the inclusion of children in specialized service care, weaknesses persist in the provision of continuous care, resulting from gaps in integration with other RAS services. These findings corroborate the results of a study with health professionals from a home care service in southern Brazil, which demonstrated that communication with health units has the sole purpose of informing the admission or dismissal of children from the service, and there is rarely exchange of information about the care provided between these two moments⁽¹⁹⁾.

Regarding weaknesses, it should also be said that the gaps in integration between the different points of care in the network, in addition to constituting barriers to the care of children with chronic conditions, impair the quality of care and expose weaknesses in the process of organization and care management of the RAS.

An important aspect regarding preventive actions is related to the lack of coordination of care evidenced by the health demands of children with CZS not absorbed by PHC. Systematic review on the quality of care for children aged zero to five years, in PHC in Brazil, found the existence of limitations in access to these services, as well as weaknesses in the family and community approach as a consequence of the deficient training of human resources in these care settings⁽²⁰⁾. The difficulty in accessing high quality care, especially for children with special health needs, is still a challenge, even in countries with bold policies in favor of universal coverage, accessibility and quality of care. In Thailand, for example, the 43 families of children with special needs living in rural areas who participated in a Grounded

Theory study revealed that the main problems related to care to these children were the lack of support from professionals and geographical issues (distances) from health services⁽²¹⁾.

A study on the support network of caregiver mothers found their dissatisfaction with the care service closest to their home, which led them to seek care in a specialized service, despite the fact that this causes inconvenience, due to the greater distance to be covered to the aforementioned specialized service⁽²²⁾. Among the reasons that motivate families to seek these services, the following stand out: parents' trust in the health professionals who work there, expectations about the quality of care provided, personal and/or social network experience and satisfaction with the service^(22,23). Therefore, it is inferred that it is necessary to expand strategies beyond public policy makers, in order to involve educational institutions in the training of professionals committed to strengthening PHC.

Given the weaknesses found in the continuity of care for children with CZS in the RAS, it should be stressed that families are reluctant to disengage from specialized services, reporting that, sometimes, PHC professionals are unaware of the health demands of these children and their families, as the links were built with the services that families initially accessed most, the secondary and tertiary levels of the SUS⁽²⁴⁾.

Another relevant aspect concerns the fact that families assisted by the specialized rehabilitation center perceive this service as more qualified than other RAS services, in addition to idealizing the concept of lifelong rehabilitation for affected children. Thus, sometimes therapeutic centers are used simultaneously, which can generate overload, increase costs without improving resolution, in addition to hindering access for children with similar health problems, who do not have effective monitoring due to access problems, such as lack of vacancy, schedule and health professional⁽¹⁵⁾.

One aspect that favors the discontinuity of care for children with CZS after discharge from the specialized service is related to the way these families are received at RAS health care points, sometimes marked by a lack of concern about the difficulties faced by them⁽⁴⁾. Therefore, it is essential to invest in horizontal relationships between health professionals and people with chronic conditions, through welcoming and dialogue.

Given the lack of follow-up highlighted by the professionals in this study, it should be said that barriers to accessing specialized care services are obstacles to comprehensive and continuous care for children with CZS, who commonly face long waiting times for exams and specialized consultations. This can generate, among other consequences, harm to the health status of these children, who, while waiting for care, may experience a worsening of their clinical condition⁽²⁵⁾. Once included in the health service, these children can be monitored in

telerehabilitation programs, which can provide an expansion in the continuity of care and adequate support for children with special needs and their families⁽²⁶⁾ and, at the same time, open space for other children to have access to specialized services. However, a monitoring protocol is necessary in which face-to-face care is provided with a frequency defined according not only to the child's progress, but also to the training of their caregivers.

The obstacles related to slow access to specialists, added to the distance between the demand and supply of care to these children in the RAS, lead to the search for alternative access to guarantee continuity of care. These accesses include the increase in the search for private health insurance plans to benefit from certain services, such as physiotherapy and consultations in times of need⁽²⁵⁾, as well as the replacement of PHC services with care in emergency care units^(16,27).

The need to reorganize the network's health services is considered, with actions that provide agility in the processes of diagnosis, referral and treatment of children with CZS, with emphasis on the strengthening of the health regulation process. A study points out that the fragility in this process often results from the turnover of managers and health professionals, especially in PHC, due to the type of hiring. This turnover, can actually directly compromise the longitudinality of care and be a factor of dissatisfaction with care⁽⁷⁾.

Among the perceived potential in assisting children with CZS in the RAS, the fact that any PHC professional can refer these children to specialized services stands out, and therefore doctors are not the only ones involved in the referrals and treatments of this population. This demonstrates progress in valuing multi- and interdisciplinary care, and in the construction of an organized network with an agile and decentralized flow to meet the demands of those living with chronic and complex diseases⁽¹²⁾.

Another potential mentioned was the recognition of the importance of PHC in coordinating the continuity of care for children with CZS. In fact, PHC can cover the population's health problems, in a regionalized way and coordinated with public policies, with a focus on health promotion and disease prevention. When PHC integrates a broad, coordinated care network with well-defined flowcharts, it is capable of effective action in tackling chronic conditions, contributing to disease control and reducing avoidable hospitalizations^(5,27).

In this regard, childcare, early stimulation actions, referral to specialized assistance and identification of families at social risk are strategic care actions for children with CZS and their families, which can be developed by PHC professionals⁽²²⁾. The professionals in the referred study also mentioned integration/communication between the different points of the

network as a potential aspect in the care of children with the syndrome. Protocols were suggested to guide the communication process, with the aim of avoiding uncoordinated interventions and guidelines that make it difficult to understand families and their attitudes towards the well-being of children⁽²⁸⁾.

Among the strategies to enhance communication between health professionals, a study based on experiences developed in the United Kingdom stressed the use of digital health care resources. The use of information technologies needs to be recognized as a facilitator to improve patient experiences and the quality of healthcare services⁽²⁹⁾. As an example, the use of virtual social networks as a space for exchanging experiences is cited, both regarding care actions and the search for treatment in the face of chronic conditions⁽²²⁾.

Furthermore, the shared use of electronic health records between public and/or private healthcare providers could minimize this situation, in addition to considering that the data generated by these tools as by-products of care can be used to support public policies and care planning. aimed at the singularities of children with SCZ. Furthermore, the operational structure and a logical operating system are constituent elements that are important for the operationalization of the RAS.

Another aspect highlighted as potential is the possibility of providing guidance to families regarding the search for care at different levels of health care in the SUS, according to the degree of complexity of children with CZS. This is because in the face of an exacerbation of a child's chronic condition, or even in the face of an acute condition, most parents tend to preferentially access specialized services where the child is already being monitored. However, these services have limited resources, and access to them should only be reserved for times when specialized experience is, in fact, necessary.

After discharge from the specialized service, continued care for children with CZS must occur in line with the referral and counter-referral system, considered one of the key elements for organization and follow-up of care. This system is capable of benefiting children with chronic conditions and their families, as it allows the early identification of clinical disorders, a segment of systematized and uninterrupted care, which aims to minimize damage to health and contribute to improving the quality of life of those involved⁽³⁰⁾.

To change this reality, it is necessary to create a stronger care network, made up of health services that assist children and their families, in a multidisciplinary and longitudinal way, that values bonds, with active and humanized listening, as well as the qualification of health professionals⁽⁶⁾. Therefore, the need for Primary Health Care teams to be prepared for more efficient action with these families is reiterated.

Possible limitations of this study are the fact that it only involved specialized care professionals and that it did not include members of all professional classes who work in the service, especially nurses, since these are often the ones who coordinate care actions at different levels of care. The lack of time to participate in the study reflects some of the excess work faced by nurses in their daily work at all levels of care. However, the findings can support the development of specific public policies for these children and many others who live with a chronic condition, considering their unique health care demands from a multidisciplinary, comprehensive and continuous perspective.

FINAL CONSIDERATIONS

The assistance offered to children with CZS, from the perspective of specialized health care professionals, presents weaknesses and potentialities regarding the continuity of care in the RAS. Although discontinuity of care is a frequent finding in the literature, in this specific case, it is caused by the lack of qualified professionals to meet the needs of this clientele. There are weaknesses in the connection of points in the network and in the capacity of this network to optimize access and follow-up of assistance at different points of care.

When family caregivers are referred to Primary Care services, they are reluctant to accept these services because they do not feel welcomed and confident that the specificities of the care needed by these children will be met. The lack of integration between the different services that make up the support and care network for children with CZS contributes to this difficulty. Since the scenario where this study was developed is one of the national references for the care of children with CZS, it is necessary to investigate practices in other scenarios to counter or corroborate these findings.

The professionals recommended as strategies to enhance, in practice, the maintenance of this assistance, the strengthening of the regulatory system and greater integration between the different health care points, in order to overcome the barriers to access and follow-up of these children in the RAS. Therefore, it is necessary to consider the importance of humanized, comprehensive and coordinated care actions that include treatment, surveillance, disease prevention and health promotion for children with the syndrome in the three levels of SUS care, in particular, in PHC. Furthermore, care actors must embrace their role, especially with regard to the implications for nursing, as nurses are supposed to coordinate the organization of care for this population in the context of the RAS.

Finally, the findings of this study are relevant and should be considered in the training of future professionals, as well as in the ongoing education of those who work in RAS

services. The aim is to reflect on the importance of communication/integration between different professionals and RAS care points in the assistance of this population, implementing the referral and counter-referral system for the longitudinality of care. To better understand how this assistance is provided, it is suggested that future studies prioritize the participation of nurses and family caregivers of these children.

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