

# Continuity of neuro-psychomotor stimulation of children with congenital Zika syndrome

*Continuidade da estimulação neuropsicomotora de crianças com síndrome congênita do Zika*  
*Continuidad de la estimulación neuropsicomotora de niños con síndrome congénito del Zika*

**Anna Tereza Alves Guedes<sup>1</sup>**

ORCID: 0000-0002-9495-4942

**Anniely Rodrigues Soares<sup>1</sup>**

ORCID: 0000-0002-3382-671X

**Daniele Beltrão Lucena de França<sup>1</sup>**

ORCID: 0000-0003-1886-0474

**Elenice Maria Cecchetti Vaz<sup>1</sup>**

ORCID: 0000-0001-6149-1892

**Neusa Collet<sup>1</sup>**

ORCID: 0000-0002-4795-0279

**Altamira Pereira da Silva Reichert<sup>1</sup>**

ORCID: 0000-0002-4295-6698

## ABSTRACT

**Objective:** Understand the continuity of stimulation of neuro-psychomotor development in children with congenital Zika syndrome. **Method:** Descriptive-exploratory study with theoretical support in symbolic interactionism. Between August and November 2019, 12 health professionals were interviewed in depth; and to the focus group, seven caregivers of children with the syndrome. The analysis was thematic inductive. **Results:** The continuation of neuro-psychomotor stimulation of children with Zika syndrome goes through: organizational difficulties (lack of doctors, professional unpreparedness, dissatisfaction and search for other services); socioenvironmental aspects (low maternal education, low socioeconomic level, difficulty in moving and lack of support); and conditions inherent to children (hospitalizations for respiratory crises, seizures, hypoactivity and social stigma). **Final considerations:** A strengthened support network with qualified human resources is necessary in order to provide comprehensive care and avoid the discontinuity of neuro-psychomotor stimulation of children with congenital Zika syndrome.

**Descriptors:** Zika virus; Child Care; Continuity of Patient Care; Child Development; Symbolic Interactionism.

## RESUMO

**Objetivo:** Compreender a continuidade da estimulação do desenvolvimento neuropsicomotor de crianças com síndrome congênita do Zika. **Método:** Estudo descritivo-exploratório com sustentação teórica no interacionismo simbólico. Entre agosto e novembro de 2019, foram submetidos a entrevista em profundidade 12 profissionais de saúde; e ao grupo focal, sete cuidadoras de crianças com a síndrome. A análise foi temática indutiva. **Resultados:** A continuidade da estimulação neuropsicomotora de crianças com síndrome do Zika perpassa por: dificuldades organizacionais (carência de médicos, despreparo profissional, insatisfação e busca por outros serviços); aspectos socioambientais (baixa escolaridade materna, baixo nível socioeconômico, dificuldade de deslocamento e falta de apoio); e condições inerentes às crianças (hospitalizações por crises respiratórias, convulsões, hipoaquividade e estigma social). **Considerações finais:** Faz-se necessária uma rede de apoio fortalecida e com recursos humanos qualificados, a fim de proporcionar um cuidado integral e evitar a descontinuidade da estimulação neuropsicomotora de crianças com síndrome congênita do Zika.

**Descritores:** Zika Vírus; Cuidado da Criança; Continuidade da Assistência ao Paciente; Desenvolvimento Infantil; Interacionismo Simbólico.

## RESUMEN

**Objetivo:** Comprender la continuidad de la estimulación del desarrollo neuropsicomotor de niños con síndrome congénito del Zika. **Método:** Estudio descriptivo exploratorio basado en el interaccionismo simbólico. Entre agosto y noviembre de 2019, sometidos a entrevista en profundidad 12 profesionales de salud; y al equipo focal, siete cuidadoras de niños con el síndrome. Análisis temático inductivo. **Resultados:** La continuidad de la estimulación neuropsicomotora de niños con síndrome del Zika pasa por: dificultades organizacionales (carencia de médicos, falta de preparación profesional, insatisfacción y búsqueda por otros servicios); aspectos socioambientales (baja escolaridad materna, bajo nivel socioeconómico, dificultad de desplazamiento y falta de apoyo); y condiciones inherentes a los niños (hospitalizaciones por crisis respiratorias, convulsiones, hipoaquividad y estigma social). **Consideraciones finales:** Se hace necesaria una red de apoyo fortalecida y con recursos humanos cualificados, para proporcionar un cuidado integral y evitar la discontinuidad de estimulación neuropsicomotora de niños con síndrome congénito del Zika.

**Descriptor:** Zika Virus; Cuidado del Niño; Continuidad de la Asistencia al Paciente; Desarrollo Infantil; Interacionismo Simbólico.

<sup>1</sup>Universidade Federal da Paraíba. João Pessoa, Paraíba, Brazil.

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## Corresponding author:

Anna Tereza Alves Guedes  
E-mail: [annaterzag@gmail.com](mailto:annaterzag@gmail.com)



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## INTRODUCTION

The Zika virus (ZIKV) outbreak ceased in the Americas at the end of 2016. However, it remains a public health problem<sup>(1)</sup>. In Brazil, up to October 2019, 3,474 cases of new-borns (NB) with microcephaly and/or congenital Zika syndrome (CZS) were registered, the majority being in the Northeast Region (56.9%), mainly in the states of Pernambuco, Bahia and Paraíba<sup>(2)</sup>. CZS is a set of signs and symptoms of neurological development related to congenital ZIKV infection, which can be revealed during prenatal or early childhood. This implies vast associated conditions that include brain malformations, seizures, irritability, difficulty swallowing, contractures in the limbs and hearing and visual changes<sup>(3)</sup>.

This situation leads to a general impairment of development, and the severity of the manifestations depends on the moment when the mother was affected by the infection, causing more damage to the foetus in the first trimester<sup>(4)</sup>. Thus, children's neuro-psychomotor development should be stimulated by interdisciplinary professionals<sup>(5)</sup> and among your family members; they need to be accompanied so that they have the chance to prosper and, consequently, have a good quality of life.

To be successful in the process of stimulating development, it is necessary that activities be continuous. In this context, there must be action-interaction between health professionals, the user and the family, aiming to achieve objectives and goals in a shared way, in which the care actions are modified in the interaction with all involved, transforming perspectives and beliefs<sup>(6)</sup>.

Development should be stimulated, especially in early childhood, a period when there is greater brain plasticity. However, this moment is also influenced by the environment where the child is inserted, as solid foundations enable healthy development. In contrast, adversities are gaps making it difficult for the child to acquire more skills<sup>(7)</sup>.

According to the World Health Organization (WHO), poverty, stigma, discrimination, violence, child neglect and difficulty in accessing health services are obstacles for children to be stimulated effectively in early childhood<sup>(8)</sup>. In addition to these difficulties, those with a disability are not supported in their development process, mainly because of the unpreparedness of health services to accompany them<sup>(9)</sup>.

This fact can be observed in the epidemiological bulletin of the Ministry of Health (MS) of March 2019, according to which, of the 3,332 confirmed cases of children with CZS, only 34.9% were in early stimulation in the rehabilitation service<sup>(10)</sup>. This low rate reflects an unfavorable prognosis for children with disabilities, poor quality of life and, therefore, family burden.

Caregivers will certainly need family, professional and organizational support to face the challenge of caring for and following up on child development stimulation activities<sup>(5)</sup>. Thus, the MS organized care linking public policies related to Child Health, Health of People with Disabilities and Primary Care, in order to associate different services and ensure welcoming, diagnosis and treatment for this population<sup>(11)</sup>.

In addition to these policies, other initiatives have been taken by the Ministry of Health to ensure the stimulation of the development of children with CZS, such as *Early Stimulation Guidelines*

*Children from zero to three years old with delayed neuro-psychomotor development due to microcephaly and the Inclusion Networks Project*<sup>(12-13)</sup>. In addition, in 2017, Specialized Rehabilitation Centers (SRC) were opened in numerous municipalities, and the right to a lifetime pension was guaranteed for children with CZS<sup>(2)</sup>.

Despite these efforts, a study points out that it is common for caregivers of children with disabilities not to cooperate with the continuation of development stimulation, because they do not recognize themselves as competent subjects for this purpose<sup>(14)</sup>. There may also be a failure in communication or reception between rehabilitation services and the family: for example, if caregivers feel judged or if their children are ignored during the visits<sup>(15)</sup>.

Therefore, understanding the factors that lead to the discontinuation of the stimulation of neuro-psychomotor development is an important aspect to be investigated, given that they are unnoticed in the daily routine of services. There are also tiny studies that address the needs of caregivers of children with developmental delay in order to improve their children's participation in rehabilitation therapies<sup>(16)</sup>.

Considering the above, the question arises: How does the stimulation of neuro-psychomotor development of children with congenital Zika syndrome occur? Based on the aforementioned aspects, it is understood that this study is extremely important to improve the rehabilitation services of the Unified Health System (SUS) and bring benefits to the health care of this population.

## OBJECTIVE

Understand the continuity of stimulation of neuro-psychomotor development in children with congenital Zika syndrome.

## METHODS

### Ethical aspects

The project was approved by the Research Ethics Committee of a public institution in the Northeast. All participants signed the Free and Informed Consent Form, respecting the criteria established in Resolution 466/12 of the National Health Council, in force in the country.

### Type of study and theoretical-methodological framework

Qualitative, descriptive-exploratory research, which used symbolic interactionism (SI) as a theoretical framework, as it makes it possible to unveil the relationships and interactions between professionals and users/family in the perspective of continuity of care<sup>(6)</sup>.

For interactionists, social behavior is based on individual experience, based on the assumption that the human being understands the environment in which he is inserted in the interaction with others. This theory enables the understanding of what human beings are, their actions, the way individuals interpret people and objects with which they interact<sup>(17)</sup>.

For the construction of the manuscript, the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

## Study setting

The research scenario was three public institutions, two state and one municipal, in a capital of the Northeast of Brazil, references for monitoring and stimulating the neuro-psychomotor development of children with CZS.

## Data source

In order to achieve the objectives of the study, the elected participants were caregivers of children with CZS and professionals working in the rehabilitation centers. The intentional and convenience sample was determined by theoretical saturation, which was ratified as thematic convergences and recurrences occurred. No new data, new properties or new dimensions have emerged<sup>(18)</sup>.

To select the caregivers, the inclusion criteria were adopted: being the main caregiver of children with CZS; being absent or with low attendance in neuro- psychomotor stimulation sessions; reside in the municipality where the study was conducted or in surrounding cities; and be over 18. And for professionals: work in one of the institutions listed for the study; and answer for children with CZS who were not regular or absent from the service.

As exclusion criteria, it was established for caregivers: not having the ability to understand or having difficulty communicating. And for professionals: to be on vacation or leave during the data collection period. Caregivers were considered absent when they missed three or more scheduled appointments and were disconnected from services.

## Collection and organization of data

Data were collected between August and November 2019, through an in-depth individual interview with professionals, and a focus group (FG) with caregivers.

The interviews with the professionals were carried out in the services themselves, in a quiet physical space and with privacy, and lasted, on average, 30 minutes. The instrument used characterized the professionals regarding age, sex, profession and experience of stimulation with children with CZS; and was guided by the question: Why are the caregivers of the child with CZS absent or with low attendance at the neuro-psychomotor stimulation service?

To collect data with the caregivers, it was necessary, first, a survey among the coordinators of the three institutions to identify those who are absent or with low attendance in neuro-psychomotor stimulation sessions. Given this information, an invitation was made to them, via telephone contact; and, for those who showed interest and availability to participate in the study, a group of cell phone applications was created in which information about the FG was passed on.

The FG occurred in a meeting with seven caregivers, in a welcoming, reserved and silent environment, at a public higher education institution, with the necessary audio-visual resources (data show, computer and recorder). Initially, the main researcher exposed a video that addressed the reality of caregivers of children with CZS in a scenario similar to that of the study participants,

a moment that triggered a reflection and consequent exposure of experiences. The discussion was augmented by the guiding question: "What led you to be absent/or with low attendance at your children's neuro-psychomotor stimulation service?" The FG lasted an average of 60 minutes.

Both GF narratives and interviews were recorded using portable digital media and transcribed in full for systematization and analysis. In the FG, in addition to the audio, the non-verbal expressions of the participants were recorded in the field diary. To guarantee the confidentiality of the information, the caregivers were represented by the letter C, followed by a numerical order from 1 to 7 (C1, C2, ..., C7). The professionals were coded according to their professions, followed by the chronological number of the interview (FI-physiotherapist, FO-speech therapist, MU musician, TO-occupational therapist).

## Data analysis

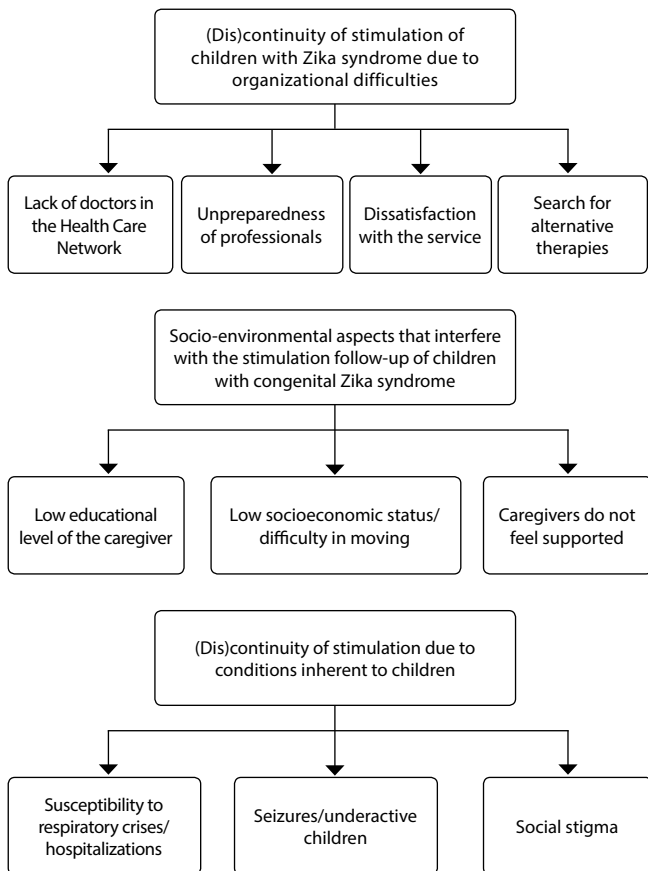
The empirical material was submitted to inductive thematic analysis, and the identified themes were extracted from the data itself. The operationalization followed the six stages of analysis: familiarization with the theme, from the active reading of the empirical material before the search for codes and meanings; generation of initial codes, with the identification of similar sets and production of initial codes manually; search for themes, with the selection of different codes on potential themes; review of the themes, in which they were refined by reading all the data extracts that were part of each theme and visualizing the relationship between the themes; definition and naming of the themes, with their clear identification; and production of the final text<sup>(19)</sup>.

## RESULTS

Of the 19 study participants, 12 were professionals working in rehabilitation centers, and 7 were caregivers for children with CZS. Among professionals, age ranged between 25 and 64 years, and only two were male. As for specialties, there were six physical therapists, three occupational therapists, a musician and two speech therapists. Most had three and a half years of experience in stimulating the development of children with CZS, that is, they had the opportunity to accompany these children from the first days of life.

In relation to the seven caregivers, all were mothers, aged between 22 and 41 years. The children were in the age range of 2 years and 11 months to 3 years and 11 months. Three caregivers had up to four years of study; and four were over eight years old. Most received a minimum wage, and two received two minimum wages. In addition, four had only one child, and three had three children. As for marital status, there were two in a stable relationship, two single, one divorced, and two married.

From the analysis of the extracts, three thematic units were elaborated (Fig. 1): (Dis)continuity of stimulation of children with Zika syndrome due to organizational difficulties; Socio-environmental aspects that interfere in the follow-up of stimulation of children with CZS; (Dis)continuity of stimulation due to conditions inherent to children.



**Figure 1** – Thematic map containing the three main themes and the respective data extracts, João Pessoa, Paraíba, Brazil, 2020

**(Dis)continuity of stimulation of children with Zika syndrome due to organizational difficulties**

The results showed that the actions of professionals and the infrastructure of the services interfere with the continued stimulation of children with CZS. In this sense, one aspect concerns the lack of doctors to assist children when they have some morbidity.

*When I took her to therapy, she had a crisis there, so she was told to control the crisis so she could return. I'm trying to control the seizures, but I haven't been able to see the neurologist for three months. (C5)*

*There should be better monitoring in the SUS network, in relation to specialist doctors in the area to better monitor these children, to prevent diseases, especially of the respiratory tract, which is what they have the most. And we have these doctors absent from the network. (TO1)*

Despite the shortage of doctors in the Health Care Network (RAS), the rehabilitation centers expanded in the municipality studied. However, the professionals who work in these centers are not yet prepared to encourage children with CZS.

*It doesn't help the stimulation centers to have only a physical structure similar to institution A, they have to train people because these children have a window of development: if we delay in that window, we've lost something, and it may be late. (F12)*

*The point is not to have 300 places for you to go, it is the professional training that you don't have. Because the stimulation of these children has to be differentiated. So much so that the evolution of children in Municipality X is much better than those here [in the capital] because the professionals trained there. It is not the lack of place or the lack of professional, but the lack of training that they lack. (C4)*

Caregivers are dissatisfied with the care offered by the rehabilitation centers. For this reason, they choose and seek other alternatives in order to stimulate the child's development, such as hippotherapy and care in a religious community.

*All his physiotherapists only stretched him and nothing else. In the six months he has been on hippotherapy, he has had an evolution that he has not had in a year with physical therapy. Then I didn't take it anymore, I decided to disconnect from everything. In the religious community, I also see evolution much better than in institutions A and B. (C4)*

*To this day, they only stretch [professionals from institutions A, B and C]. I started at Bobath [method to improve disorders of function, movement and postural control] in the religious community with my son just now, and she [professional] said: "Mom, he is not supposed to be doing more stretching, now we need to work for him to stand, to sit". And the institutions were doing none of that. So, I'm going to make an effort to take it twice a week, because what I want most is for him to support that head. (C7)*

**Socio-environmental aspects that interfere with the stimulation follow-up of children with congenital Zika syndrome**

For neuro-psychomotor stimulation of children with CZS to be effective, it must be done in a shared way between the service and the family. However, the low education level of the caregivers was one of the obstacles to continue this practice, as they do not feel competent to proceed to stimulation and do not have enough information about the child's health condition.

*Although we are guiding the parents, they say "We can't do it like you do", because many have a very low level of education. (F12)*

*So if the professional who was there half an hour was no longer able to do it, I wish I didn't even know what microcephaly was. (C4)*

Another difficulty widely mentioned among caregivers and professionals was the low socioeconomic status and, consequently, the difficulty of commuting to therapies due to the lack of adequate means of transport, as the children are large and heavy.

*Because of the socioeconomic issue, they are unable to come. Most of them live very far away, so to come with the child in their arms, a heavy child, it ends up being difficult and they leave one of the appointments aside. They always choose one in the week and go, and don't go to the other. (MU1)*

*My son had been in three appointments for 15 days, but now my husband was without a car and it is very complicated to take because he has to pay for a car, because of the weight he cannot ride a bus, and then each day R\$ 50.00 and it's not every day that we have it. (C3)*



The fragility of support is another obstacle to the continuation of neuro-psychomotor stimulation, as the mothers of children with CZS have other children to care for. Husbands often leave the family, and they are overwhelmed physically and psychologically.

*My difficulty is because I have two children and only his father and I live, so I have to take care of both of them and her, so I left the therapies. (C1)*

*There are some who go and return over time, it is very personal, it also depends on the interaction they have, the support. Because there are some or most that the father does not live with the child, and that disturbs a lot, it's all the mother, and other children who already have. (F13)*

*[...] Most mothers ... I speak mothers because most children are accompanied by mothers, very rare by parents or both. (FO2)*

### **(Dis)continuity of stimulation due to conditions inherent to children**

The child with CZS has some signs and symptoms that professionals consider as obstacles to the continuation of stimulation of development. One of the aspects mentioned was the susceptibility to respiratory crises due to the clinical condition and age, which leads to frequent hospitalizations. Therefore, during the hospitalization period, there is discontinuation of therapy and even regression of skills that had already been achieved.

*Sometimes, low immunity causes children to get sick frequently and, therefore, they are hospitalized routinely. There are children who have recurrent attacks of pneumonia and then that time in the hospital, they no longer come to my therapy, they start missing and then the child's [neuro-psychomotor] condition regresses. (F11)*

*My daughter has low immunity, every little thing gets the flu, every week it's a flu because of immunity. (C6)*

Another aspect that contributes to the regression of the skills acquired by the child is the seizure crisis. According to the professionals, the medications leave the children underactive, making the therapy difficult.

*Children have already regressed in posture, in tone mainly after seizures, from the moment they started to have more seizures. The medications they have taken to reduce spasms make them more inactive, and this hinders rehabilitation. (F12)*

In addition to the signs related to child health, social stigma was pointed out by caregivers and professionals as a barrier to the continuation of stimulation.

*There are mothers who do not go anywhere because they do not want to expose their children, some comment that when they come here, on the bus, people keep asking with an indifferent look, so that already inhibits them too. There are people who get away; a mother said that they asked: "What does she have? And where are you going?" There are mothers who respond in a good way, but there are others who are shocked, hurt, cry. (F13)*

*I already had a situation, right at the beginning, a lady asked me: "Is that a boy, is it?" As if to say he is an extra-terrestrial. Ah, we have been through many. (C3)*

### **DISCUSSION**

The aspects that lead to low attendance or absence in therapies and interfere with the continuity of neuro-psychomotor stimulation of children with CZS go through organizational barriers, socio-environmental aspects and conditions inherent to the child. Attention to people with disabilities must respond to their different health needs, linked or not to disability.

As well as rehabilitation, health promotion and disease prevention are of paramount importance for monitoring<sup>(20)</sup>. In this sense, for the health of the child with CZS to be considered in its entirety, the following are fundamental aspects: the link between the Specialized Centers in Rehabilitation and Primary Care (PC), as well as assistance by a multidisciplinary team<sup>(11)</sup>.

Continuity of care implies interaction between different professionals and an interdisciplinary team or between different services and institutions, in order to guarantee comprehensive care. For this, professionals and services must act in an articulated manner, according to the health needs of users/family members<sup>(21)</sup>.

With a view to expanding the access of children with CZS and their families to different points of assistance, the MOH has implemented new CERs in several municipalities, in order to ensure an early and effective neuro-psychomotor stimulation<sup>(2)</sup>. Even so, in this study, the data allow to affirm that there is a lack of training of professionals in the rehabilitation services to meet the specificities of these children, which has resulted in the dissatisfaction of the caregivers and, in turn, in the compromise of the continuity of stimulation in these attention points. This assertion was also verified in a study developed in Pernambuco and Rio de Janeiro, according to which the mothers of children with CZS and health professionals considered health care insufficient and fragmented<sup>(22)</sup>.

Caregivers were dissatisfied with the assistance offered by the RECs, which resulted in the search for alternatives, such as equine therapy, a therapeutic method in which the interaction with horses provides biopsychosocial development for people with special needs<sup>(23)</sup>; and Bobath, a method used to improve disorders of function, movement and postural control<sup>(24)</sup>. Therefore, despite the obstacles to the continuity of stimulation, when the caregivers perceive the children's development evolution and feel satisfied with the care, they re-signify the symbol of the therapies, that is, they modify their individual behavior, and their conduct is to continue with therapies<sup>(17)</sup>, but in other spaces and possibilities.

Regarding the socioenvironmental aspects that interfere with the follow-up of stimulation of children with CZS, it was found that the caregivers feel insecure to continue with the stimulation due to low education and little clarification about the CZS. Research corroborates this aspect by showing that the engagement of children with physical disabilities in stimulation services is more influenced by environmental factors (such as social support, financial resources and level of family knowledge) than by the type of disability<sup>(14)</sup>.

Research carried out in Barcelona with children with intellectual disabilities showed that more effective results in child development depend on the level of family education. Thus, it was observed that

language acquisition was better in children of mothers who had a university degree than in those who only finished high school<sup>(25)</sup>.

According to symbolic interactionism, human action is not derived only from interaction with others, but also from an internal reflective process of each individual, as the human being brings with their own convictions and perspectives that guide their actions; these, regarding the subject in question, occur with regard to the conduct taken in the care directed to the child with CZS and in the continuity of this<sup>(17)</sup>. So, low education and little understanding about the child's health condition may influence the caregivers' reflective process on the importance of following up on stimuli, whether at home or in rehabilitation services.

In addition, based on the results of this study, it can be stated that the non-attendance to services is also due to the socio-economic condition of the families, especially with regard to the displacement of the home for therapies. This happens because of the distance between the home and the CERs and the difficulty in carrying the children due to their size and weight, making it impossible to get around by public transport. A similar reality was found in a study with caregivers of children with microcephaly in Salvador, which pointed out that most caregivers survive on a minimum wage and generally travel by bus to the appointments, making it difficult to attend consultations<sup>(26)</sup>.

In view of the socio-environmental difficulties encountered, it is understood that it is necessary to strengthen support for caregivers of children with CZS, which was not evidenced in the current study. The caregivers justify the non-attendance to the stimulation services because, in addition to the care for other children, the abandonment of the spouse and the physical and psychological overload, they do not have family or social support.

Although the stimulation services offer family-centered attention, the mother is usually the main family caregiver and, in turn, has higher levels of anxiety and depression. In addition, families of children with disabilities also report marital dissatisfaction and poor quality of life. For this reason, the professional must have an interactional and family-centered approach in order to increase the competence and trust of the parents, encouraging positive perceptions regarding the care of the child, such as affection. This is justified because the affection of parents provides better cognitive skills and prepares for life in the community<sup>(25,27)</sup>.

Therefore, according to SI, the action-interaction between health professionals and users/family is essential for continuity of care. The user/family conceives specific care actions and, when interacting, interprets perspectives, apprehends expectations mutually with those involved in this process and articulates their actions<sup>(6)</sup>.

Another obstacle to the continuity of care for children with CZS are the obstacles inherent to their health condition, such as respiratory crises and seizures, which, at various times, lead to hospitalizations, reduce the time taken to attend the stimulation services and/or result in discontinuity of therapy, with a consequent regression of acquired skills.

Children with CZS are more vulnerable to infections, especially respiratory infections, due to the association between dysphagia and spasticity. Therefore, when they are sick, they should be assisted as soon as possible because they are at greater risk of morbimortality<sup>(3)</sup>. There was consensus in the data extracts that, when children are hospitalized to treat respiratory conditions,

stimulation is interrupted, and neuro-psychomotor development regresses. In accordance with this statement, the literature reveals that the child's hospitalization has repercussions on development due to the distance from the family environment, changes in routine and emotional disorders<sup>(28)</sup>.

Furthermore, due to brain malformations, more than 50% of children with CZS are at high risk of having seizures in early childhood, a fact that can also lead to interruptions in therapies. In this situation, in order to carry out the treatment without interruption, the goals must be drawn between professionals and caregivers, in order to balance crisis control and minimize side effects of medications, such as excessive sedation<sup>(3)</sup>.

Finally, social stigma is one of the obstacles to children's access to stimulation services. In line with this, research conducted in New York has shown that individuals with CZS will face stigma and that a woman with a child with microcephaly or another disability can be stigmatized. Reflections on the individual can include feelings of discrimination, exclusion and stress, which can lead to isolation of the person and families and prevent access to education and health services<sup>(3)</sup>.

A study carried out in a US capital city with parents of children with disabilities found that the lower the parents' level of education, the higher the level of embarrassment because of social stigma. In addition, the father and mother are more likely to develop mental and physical health problems, such as depression, higher body mass index and activity limitations<sup>(16)</sup>.

This context of discrimination on the grounds of disability is old, but it persists to the present day and interferes in achieving equal opportunities for this population. So, it is essential that the human being reframe this perception; for this, symbolic interactionism defends the importance of putting oneself in the other's place and acting as he would<sup>(21)</sup>.

### Study Limitation

The limitation consisted of recruiting participants, as it was restricted to three public services in a capital city of Northeast Brazil, which did not demarcate the affirmation of this reality in other geographical contexts and/or health services.

### Contributions to the field of Health

Understanding the continuity of neuro-psychomotor stimulation of children with CZS contributes to the theoretical advancement of the topic in question. This research provides subsidies so that managers, professionals and caregivers involved are both sensitized with regard to the obstacles that lead to discontinuity of stimulation and seek these children with CZS and their families, in order to modify this reality and improve the quality of life.

### FINAL CONSIDERATIONS

This study revealed that there are several obstacles to achieving success in the continuation of neuro-psychomotor stimulation of children with CZS, such as organizational barriers, socio-environmental factors and difficulties imposed by the child's clinical condition. The reasons that lead children with CZS to be

considered absent or absent in the consultations of rehabilitation centers are verified. However, it is also evident that caregivers continue to stimulate the development of these children when they feel welcomed and satisfied with the care and, thus, redefine the symbol given to the therapies, seeking alternatives such as equine therapy and philanthropic care.

To change this reality, an effective health policy, a good relationship between professionals and caregivers, interdisciplinary work, information sharing, integration and coordination of care between all levels of health care and active and responsible participation of the family are necessary. In addition, it is necessary to create a strengthened support network for families, who need

to be supported in their psychological, financial, informational demands, in order to seek more equal conditions.

It is suggested that studies be carried out with intervention design, in order to sensitize professionals about the singularities of the condition of the child with Zika syndrome and their family, so that they do not lose sight of them and guarantee the continuity of neuro-psychomotor stimulation.

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