

Microcephaly Diagnosis: Maternal Perspectives About the Organization of the Health Care Network*

Theme: Promotion and prevention.

Contribution to the subject: This research is of singular relevance for the health area and essential for the municipality under study, as it may contribute to the planning of actions that mobilize professionals in the implementation of the protocols for assistance to newborns with microcephaly, proposed by the Brazilian Ministry of Health. It may also favor reflection on the flow and organization of the municipal health care network, to enhance care in the assistance sectors for children with microcephaly and their families.

ABSTRACT

Objective: To understand the organization of the Health Care Network (*Rede de Atenção à Saúde*, RAS) from the experiences of mothers and family members in the assistance process for the diagnosis of microcephaly. **Materials and methods:** A descriptive and exploratory research study with a qualitative approach, conducted with 14 mothers of children with microcephaly. For the definition of the sample, the following inclusion criteria were listed: being a mother of a child diagnosed with microcephaly due to Zika Virus, having given birth, and being a resident of the municipality of Mossoró, Rio Grande do Norte, Brazil. Regarding the exclusion criterion, the following was specified: mothers who did not accept to participate in the study. The population of this research was defined in 2018. Minayo's method

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1 <https://orcid.org/0000-0003-3402-5065>. Universidade do Estado do Rio Grande do Norte, Brasil. hosanamirelle@uern.com

2 <https://orcid.org/0000-0003-1165-3931>. Universidade do Estado do Rio Grande do Norte, Brazil. barbaradaniely@alu.uern.br

3 <https://orcid.org/0000-0002-7340-5012>. Universidade do Estado do Rio Grande do Norte, Brazil. jussaraalcantara@alu.uern.br

4 <https://orcid.org/0000-0002-6513-120X>. Universidade do Estado do Rio Grande do Norte, Brazil. cintiamikaelle@uern.br

5 <https://orcid.org/0000-0001-8052-4725>. Universidade do Estado do Rio Grande do Norte, Brazil. fatimaraquel@uern.br

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of thematic content analysis was employed for data analysis. **Results:** The results were divided into the following categories: 1. Access to the services, exams, and professional monitoring; 2. Perception of the mothers about follow-up in the RAS. It was possible to apprehend the obstacles experienced in the RAS for the diagnosis and follow-up of children with congenital syndrome due to the Zika Virus. **Conclusions:** The difficulty of operationalizing the proposed protocol for the RAS was evidenced, either due to insufficient knowledge about the syndrome, making it impossible to maintain the organizational flow established by the protocol, or to the scarcity of hard technologies that assist in the implementation of this assistance.

KEYWORDS (SOURCE: DECS)

Microcephaly; zika virus; nursing; delivery of health care; diagnosis.

Diagnóstico de la microcefalia: perspectivas maternas acerca de la organización de la red de atención a la salud*

RESUMEN

Objetivo: entender la organización de la Red de Atención a la Salud (RAS) desde vivencias de madres y de familiares en el proceso asistencial para el diagnóstico de microcefalia. **Materiales y métodos:** investigación descriptiva y exploratoria, de enfoque cualitativo, realizado con 14 madres de niños con microcefalia. Para definir la muestra, se consideraron los siguientes criterios de inclusión: ser madre de niño diagnosticado con microcefalia resultante del virus zika, haber parido y ser residente del municipio de Mossoró, Rio Grande do Norte, Brasil. Como criterios de exclusión, se especificaron: madres que no aceptaron a participar en el estudio. La población del estudio se definió en el 2018. Para analizar los datos, se empleó el método de análisis temático de contenido de Minayo. **Resultados:** los resultados se dividieron en las categorías: 1. acceso a los servicios, a las pruebas y al seguimiento profesional; 2. percepción de las madres acerca del seguimiento en la RAS. Se logró aprehender los obstáculos vivenciados en la RAS para o diagnóstico y el seguimiento de los niños con síndrome congénito resultante del virus zika. **Conclusiones:** se evidenció la dificultad de operacionalización de protocolo propuesto para la RAS, ya sea por el conocimiento insuficiente acerca del síndrome, imposibilitando el mantenimiento del flujo organizacional establecido por el protocolo, ya sea por la escasez de tecnologías duras que auxilien en la efectucción de esta asistencia.

PALABRAS CLAVE (FUENTE: DECS)

Microcefalia; virus zika; enfermería; prestación de atención de salud; diagnóstico.

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Diagnóstico da microcefalia: perspectivas maternas sobre a organização da rede de atenção à saúde*

RESUMO

Objetivo: entender a organização da Rede de Atenção à Saúde (RAS) a partir de vivências de mães e de familiares no processo assistencial para o diagnóstico de microcefalia. **Materiais e métodos:** pesquisa descritiva e exploratória, de abordagem qualitativa, realizada com 14 mães de crianças com microcefalia. Para a definição da amostra, foram elencados os seguintes critérios de inclusão: ser mãe de criança diagnosticada com microcefalia decorrente do zika vírus, ter parido e ser residente do município de Mossoró, Rio Grande do Norte, Brasil. Enquanto critérios de exclusão, foram especificados: mães que não aceitaram participar do estudo. A população desta investigação foi definida no ano de 2018. Para a análise dos dados, foi empregado o método da análise temática do conteúdo de Minayo. **Resultados:** os resultados foram divididos nas seguintes categorias: 1. acesso aos serviços, aos exames e ao acompanhamento profissional; 2. percepção das mães acerca do seguimento na RAS. Foi possível apreender os obstáculos vivenciados na RAS para o diagnóstico e o seguimento das crianças com síndrome congênita decorrente do zika vírus. **Conclusões:** evidenciou-se a dificuldade de operacionalização de protocolo proposto para a RAS quer seja pelo conhecimento insuficiente acerca da síndrome, impossibilitando a manutenção do fluxo organizacional estabelecido pelo protocolo, quer seja pela escassez de tecnologias duras que auxiliem na efetivação dessa assistência.

PALAVRAS-CHAVE (FONTE: DECS)

Microcefalia; zika vírus; enfermagem; assistência à saúde; diagnóstico.

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Introduction

The first record of Zika Virus (ZIKV), transmitted through *Aedes aegypti*, took place in Uganda in 1947. However, it was only 60 years later that the first outbreak occurred, in Micronesia and French Polynesia and, at the time, it was not considered a risk to public health, as it mildly manifested itself, with a benign evolution. In Brazil, ZIKV had its first identification in April 2015 (1).

The situation for facing ZIKV cases in the country was worsened when noticing that, after the occurrence of the rash disease in pregnancy, there was a significant increase in cases of microcephaly, which is defined as a congenital malformation where the head circumference of the newborns (NBs) is below the standard for their age and gender (2). During the diagnostic research, a study conducted and coordinated by Celina Turchi in 2016 identified a possible relationship between ZIKV infection during pregnancy and the occurrence of microcephaly in NBs (3).

Thus, from November 2015 to February 2020, approximately 18,687 cases of microcephaly associated with ZIKV were notified in Brazil. Of these, 22 % (4,111 cases) are still under investigation, 59.2 % (11,064 cases) were discarded, and 18.7 % (3,512 cases) are confirmed (4). These data, in turn, are characterized as alarming since, between 2000 and 2014, there were 2,464 cases of microcephaly in live births in Brazil, with an annual mean of 164 cases (5).

At the same time, from November 2015 to February 2020, in Rio Grande do Norte, 558 suspected cases of microcephaly and/or other malformations related to congenital infections were notified. Of this total, 19.3 % (108 cases) are under investigation, 29.6 % (165 cases) were confirmed, and 51.1 % (285 cases) were discarded (6). In this state, until the outbreak occurred, the proportion of cases was two cases in 2010, two in 2011, four in 2012, no cases in 2013, and one case in 2014 (7).

In the municipality of Mossoró, Rio Grande do Norte, epidemiological bulletin No. 7/2020 records 87 cases in the city, of which 19.5 % (17 cases) were confirmed, 71.3 % (62 cases) were discarded and 9.2 % (8 cases) are under investigation (6). Given the alarming initial data on microcephaly, in November 2015, the Brazilian Ministry of Health classified the occurrence of this situation as a public health emergency of national importance. Therefore, with the increase in the proportion of cases, in February 2016,

the World Health Organization also declared the situation as a public health emergency of international importance (1).

To assist in facing and controlling the epidemic in Brazil, the Brazilian Ministry of Health published two protocols: the protocol for surveillance and response to the occurrence of microcephaly and the protocol for health care and response to the occurrence of microcephaly related to ZIKV infection. There was even concern with the formatting of the Health Care Network (RAS) in the perspective of states and municipalities being organized, agreeing on the steps to be taken for the diagnostic closure of suspected cases (7).

However, in Rio Grande do Norte, there were difficulties in operationalizing this network, either due to technical and scientific limitations of the working team or to the limitation of supplies and equipment to cope with the large demand. This assertion is corroborated by the fact that, even after five years since the outbreak, there are still items pending compliance with the protocol in the state, with 22 % of the children still lacking diagnostic closure (6).

The decision to develop this research was taken given the issues observed preliminarily and assuming that the RAS is fragile and not very resolute, particularly in the occurrence of microcephaly due to ZIKV. In the course of the study, it was sought to understand the organization of the RAS based on the experiences of mothers and family members in the care process for the diagnosis of microcephaly.

Materials and methods

This is a descriptive and exploratory research, as it seeks to portray the organization of the RAS for the diagnosis of children with microcephaly due to ZIKV, from their mothers' experiences. The research was carried out in the municipality of Mossoró, the second in the state with the largest number of confirmed microcephaly cases.

The population of this research was defined in 2018 based on the number of notified cases and the non-probabilistic sample of the total number of cases for that year, delimited from the cases that had already completed the stages for diagnosis based on the ministerial protocols. Consequently, notification of 94 cases was identified, with a total of 14 cases with an already defined diagnosis. Thus, to define the sample of mothers who would be part of

the research, the following inclusion criteria were listed: being the mother of a child diagnosed with microcephaly due to ZIKV, having given birth and being a resident of the municipality of Mossoró. Regarding the research exclusion criterion, the mothers who did not accept to participate in the study were not considered.

The data collection instrument was of the semi-structured interview type. The closed questions were asked to define the sociodemographic profile of the research subjects and the open ones were intended to analyze the perception of the target audience about their trajectory through the RAS and their feelings about this path.

For data analysis, Minayo's method of thematic content analysis (8) was used, in which the speeches were organized, transcribed and separated by guiding questions, proceeding to a floating reading to apprehend the meaning of the whole. Subsequently, the material was explored with an exhaustive reading of the statements, with the purpose of categorization. Regarding this stage, first, the nuclei of meaning (words or expressions that answered the guiding question) were extracted. With the nuclei of meaning highlighted in the speeches, these were clipped, without losing the context, obtaining excerpts from the interviews that answered the question. The interviewees were identified with the word "mother", followed by a number indicating the chronological order of the interviews. After that, the categories were divided and their respective discussions were carried out. The following categories were defined: 1. Access to the services, exams and professional monitoring; 2. Perception of the mothers about follow-up in the RAS.

The research observed all the ethical aspects recommended by Resolution 466/2012 of the Brazilian National Health Council. The research in question is an excerpt from a master's dissertation carried out by Hosana Mirelle Goes Silva Costa, in which it was submitted to a previous evaluation by the Research Ethics Committee of *Universidade Estadual do Rio Grande do Norte*, approved according to Opinion No. 2,080,033, and performed as prescribed by that collegiate body.

Results

The study participants and the categories generated from data analysis are presented below.

Characterization of the study participants

For a better understanding of the categories of this research, the importance is understood of presenting the mothers, subjects of this research, to facilitate the reading of the life context and the health needs presented by the group under consideration. Thus, the description of the group of mothers of children with microcephaly due to ZIKV follows.

The study had the participation of 14 mothers of children diagnosed with microcephaly, through the care network organized in the municipality of Mossoró. Of the 14 mothers who participated in the research, 71.4 % (n = 10) were 29 years of age or younger, 42.9 % (n = 6) of these women had only completed elementary school, and 71.4 % (n = 10) were married or in a stable union. In terms of personal income, 64.3 % (n = 9) of these women carried out only activities in their homes, without participating in the productive sector, as well as in 64.3 % (n = 9) of these families, in which incomes fluctuated between one and three minimum wages. It is noteworthy that, in this income, 78.6 % (n = 11) of the sample is already included, mothers who perceive the continuous provision benefit, an aid that complements income and allows reaching this data.

The results are divided into categories of analysis, to understand the obstacles that women with children diagnosed with microcephaly due to ZIKV had to face within the RAS, namely: 1. Access to the services, exams, and professional monitoring; 2. Perception of the mothers about follow-up in the RAS.

Access to the services, exams and professional monitoring

Although all mothers in this study performed some prenatal consultations, the data show that only 50 % attended at least six consultations, as recommended by the Brazilian Ministry of Health. In this context, it was found that it was the pregnant women who made six or more consultations (50 % of the cases investigated) who early detected the occurrence of microcephaly while still pregnant. It is worth mentioning that even the pregnant women who detected microcephaly during pregnancy had much of their time consumed with the difficulty in accessing the service:

Prenatal care was initiated with two months. I went to the appointments very well, but I only managed to do the ultra with

thirty-nine weeks and four days, the day she was born was that I managed. At that moment I discovered the micro, in this ultrasound. (Mother 5)

Because the health center was always lacking the nurse, when it wasn't that, it was because it was a holiday, it wasn't working, a strike... these things like that. (Mother 4)

The aforementioned difficulty persisted, even after pregnancy, when the child needed to undergo a series of procedures foreseen in the protocols for diagnostic closure of the complication.

Then there was this task force. A lot of children were discarded, so with this task force a lot of exams were done, they gave the exams in a private clinic because it had to be soon, in a week we did, I think, like six exams. (Mother 4)

Once the difficulties related to the preliminary diagnosis were overcome, according to the guidelines in the protocol, specialized consultations become indispensable for diagnostic precision concerning the syndrome itself. This other aspect was severely impaired in the organization of the network:

[...] my son has been in the waiting list for a year, got it? For an appointment with a neuropediatrician here in Mossoró. Until today, he has been in this for a year, waiting his turn. (Mother 1)

Also in the RAS and from the maternal speeches, lack of knowledge and/or unpreparedness of the professionals regarding the referrals and the need to carry out tests for diagnostic closure was observed:

[...] I did ultrasounds every fifteen days, because it presented a change and nobody knew what that change was. So, with almost seven months [of pregnancy], we really came to discover my son's microcephaly. (Mother 3)

However, there were cases in which the mother, aware of the child's diagnosis, received more attentive care, thus evidencing the sensitivity of the professionals in the face of this situation:

As we already knew about microcephaly, the team was ready to receive her, they had already guided me since I was pregnant... I was afraid... But I trusted the team. We had all the support of the procedures, I was very well assisted. (Mother 3)

In the group of this study, the cases that were not identified, even during pregnancy, were mostly detected during follow-ups C and D:

The nurse found out when I went to do C and D at the health center, as usual. She was already eight months old. I was seeing a few different things about her, only that I thought she didn't have any condition. Because there is no way for a child to leave a large hospital and not diagnose, neither a pediatrician nor a doctor to diagnose my daughter's microcephaly. (Mother 6)

I discovered his microcephaly with a routine consultation, when he was seven months old, there in the health center. (Mother 8)

Also concerning to the RAS, when asked about the laboratory and imaging tests for diagnosis, performed at the time of birth, the data show that only three mothers reported that immediate blood collection from the umbilical cord of the children was carried out. Seven mothers reported that such examinations were not performed, and four did not know how to inform.

The data further reinforce the unenforceability of the network in the region because, with the increase in the complexity of the exams for diagnostic closure, the more difficult its performance. This was noticed when one of the mothers reported the need for a placental biopsy and collection of cerebrospinal fluid. In the cases of this research, ten mothers reported not having performed this collection, while four did not know how to inform:

No exam was done, in the maternity they passed only an ultra, a transfontanellar ultra for the child. But, as they didn't do it there, I asked for permission to do it out here. (Mother 5)

If it is impossible to perform transfontanellar ultrasonography (TF-US) while still in the maternity hospital, whether due to the absence of the necessary instruments or to the reduction of the fontanelle, it is possible to perform it later, within the child's first year of life (9). When diagnostic confirmation is not performed through laboratory tests and TF-US, the Brazilian Ministry of Health indicates that a skull computed tomography (CT) without contrast (1) should be performed.

In fact, the reports of mothers who managed or, at least, tried to carry out these exams through the public network demonstrate the obstacles to its performance:

Since she was born, the CT is there in that office and has never been scheduled. (Mother 4)

I only did an exam by the SUS, which was to detect the Zika Virus, I collected the blood with a mean of 15 days after my daughter was born, the exam only came later, with a year. (Mother 9).

Perceptions of the mothers about follow-up in the RAS

Regarding this category, the mother's speeches reinforce the network's deficiency in establishing this essential link for care continuity:

We left the hospital with a report, with a report stating that he had microcephaly, but the doctors, they didn't say anything, I even made a scandal there in the hospital, inside the hospital director's office because they didn't say anything to me that it had to be done. (Mother 1)

Such data can be a sample of how much the network was not yet understood and inserted in daily work, emphasizing the importance of unveiling the knowledge of the professionals regarding this organization.

Concerning this variable, the research data show that only five mothers were referred, upon discharge from the maternity hospital, to the health services responsible for care continuity. All these doubts, anchored to the disjointed reference services, aroused a feeling of helplessness in the mothers. Such feeling can be illustrated with the following speeches:

To the health center... I went... My daughter was not ten days old, but I had no answer there, I was not advised by the health center. (Mother 3)

Only after a year did I start going to the health center, we went to the center, but we never received a home visit, and I was never advised about anything. (Mother 7)

The reports reinforce the weakness in the services and in the operational dynamics of management, with the need to promote strategies that better assist the users of the public service regarding the understanding of the organization of assistance.

Discussion

By focusing on the diagnosis of ZIKV infection and detection of microcephaly, from the analysis, it was found that prenatal care is the action that aims to monitor pregnancy for guidelines and early diagnosis of complications (10). Consequently, it is expected that the diagnosis is made in the initial stages of pregnancy.

It is a fact that prenatal care is important, especially when all consultations and examinations provided for in this process are carried out. Thus, it is possible that early discovery and good guidance within the context of prenatal care can contribute in a uniquely to the preparation and acceptance of the condition by the mother and all the family members (11).

However, the speeches reveal the inability of the network to be resolute, to give precise answers, and to meet the demands of the population in the face of this demand. So much so that, in the municipality of Mossoró, emergency actions were taken for capture and diagnosis of possible microcephaly cases. The main action in this regard was a "task force" to assist suspected cases, to minimize the delay in the consultations and exams necessary for this research (12).

Prenatal care incapable of making the microcephaly diagnosis during the gestational period plus the failure to perform fundamental tests promptly requires the presence of a neuropsychiatrist for late diagnostic confirmation. Given the alleged organization of the RAS, as well as due to the assistance protocols for the diagnosis and follow-up of the child with microcephaly due to ZIKV, the absence of the neuropsychiatrist can be associated with the inefficiency of the network concerning the necessary services and actions before that moment.

As the focus of this research is the knowledge of the aspects involved in the dynamics of the RAS for the diagnosis of microcephaly due to ZIKV, it is important to discuss welcoming and empathy in the face of the problems experienced by each family. So, in parallel with all the technical stages for diagnosis, it would be up to each professional to welcome and guide the mother and her family (13).

However, even with the detection of the syndrome during follow-ups C and D by the health professionals, the delay in the perception of the situation is evident since only after several

follow-ups there was a referral for diagnostic closure. In these cases, it is worth reflecting on how much the monitoring of growth and development has been occurring within its predicted meaning or if the emphasis does not focus primarily on the evaluation of the child growth chart, disregarding, or underestimating, the development milestones. In some situations, it was the mothers themselves, without having scientific knowledge, who began to notice changes in the child's development. It seems that the clinical evaluation, with the identification of the changes, tended to go unnoticed by the multi-professional team responsible for providing this service.

Children with microcephaly due to ZIKV tend to perform poorly in the areas of physical, motor, cognitive, visual development and anthropometric measurements. Such characteristics can, for example, cause impairment in their growth, and development when compared to children who do not present this congenital syndrome. In this perspective, such impairments must be evaluated early in the C and D consultations for better follow-up of these children to the rehabilitation and early stimulation services (14).

Follow-ups C and D seem to tend to fail to capture nuances of the child's clinical and physical changes. This condition may be related to the emphasis on growth, with a focus and concern on weight and height, disregarding, among others, aspects related to child development (15).

Thus, it can be observed that the reorganization of a RAS aimed at children diagnosed with microcephaly, based on the assistance already offered to the population, evidenced the weaknesses and deficiencies in the availability of these services. The lack of specific professional knowledge on this situation, associated with the delay in its qualification and the recruitment of qualified professionals, has worsened the complications (16). In addition to that, the structural context of the services, as well as the difficulty in knowing and learning how to deal with the RAS, contributed greatly to the difficulty in diagnosing and monitoring these children.

Also concerning to the organization of the RAS for diagnosis, the Protocol for Health Care and Response to the Occurrence of Microcephaly Related to Infection by ZIKV states that, at the time of birth and through laboratory and imaging exams, the diagnostic investigation has as its main objectives to confirm the diagnosis of congenital microcephaly and to rule out other etiologies that

cause microcephaly (1). Some of these exams must be performed in the delivery room, such as the following collections in the NB: blood from the umbilical cord (3 mL) and the placenta (3 fragments of 1 cm³ each) and cerebrospinal fluid from the NB (1 mL) (17).

Based on the negatives regarding the performance of the exams and also due to the considerable percentage of mothers who did not know how to inform about it, it is possible to infer the mother's lack of knowledge regarding the exams and the stages for diagnosis. Some of the mothers went through the network without the slightest notion of what each stage of this process represented. However, the materials published by the Brazilian Ministry of Health (17) emphasized the importance of care beyond the biological scope, based on the formation of a bond between the professionals and the mothers of these children. This would tend to make the network accessible, by promoting the necessary supplies and logic, in which these women could understand it and solve their doubts about the diagnosis stages.

As an aggravating factor for maternal lack of knowledge, regarding the need to perform laboratory exams, the transmission of scarce information by the health team professionals can be mentioned. This is linked to a lack of knowledge or even to the establishment of an environment that does not allow for dialog between professionals and mothers (18).

To facilitate diagnosis, after discharge from the maternity hospital, the Ministry of Health recommends that the TF-US be performed as a priority. This exam is defined as the first choice, as CT uses radiation at high levels and even generates the need for sedation of the NB for its conduction (1).

However, the data demonstrate the weakness of the public services in relation to the availability of these exams on time. This, in turn, enhances, for those who have resources, the search for private means for timely diagnosis; and thus, the initiation of early stimulation.

Given the reports, there is evidence of the unpreparedness of the public bodies to deal with certain situations that require more complex assistance and the use of many technologies. Since the exams considered as basic for diagnostic definition were not prioritized, fast closure of this diagnosis became impossible, which would contribute to faster and more effective performance, especially concerning development stimulation and to the minimization of possible sequelae (19).

The public health emergency installed with microcephaly resulting from ZIKV showed the current difficulty in the articulation of the health services, at different complexity levels. According to the Ministry of Health (20), when a clinical condition is declared a public health emergency, it is necessary to urgently install risk prevention and control measures to reduce public health problems.

The arrival of these children at the service was felt with insecurity, due to diagnostic uncertainty and to the obscurity in the assistance follow-up. The families sought guidelines to understand what was happening and to know which path should be outlined (21).

In this context, the care network must encourage health promotion strategies to try to reduce and overcome the impact within the family nucleus (1).

Thus, it is important to know the network, reflecting on its organization and seeking to eliminate the frequent fragmentation present in this system, as well as in the recurrent conducts by the professionals, culminating in the guarantee of its articulation, with a view to comprehensive and resolute care (22). Only in this way would it be possible to foresee care organization in an effective and expanded way, favoring access and more resolute, qualified and welcoming care for the population.

Conclusions

ZIKV increased the fragility of the organization of the services that make up the RAS in the services and in the study centers. When the demands arose, the focus was only on biological control, not paying attention to other problems. Such congenital malformation requires humanized attention from the health services, because of the social profile reached by ZIKV.

This flow requires assistance demands that range from conception to the rehabilitation of the children and their families. The aim is a network that guarantees the integrality of the care provided to this population, through the articulation of the different sectors and the commitment of the working professionals.

However, it was noticed that, according to the maternal perspective, the care network in question presented various failures in complying with the entire protocol recommended for the care of the children, pointing out the need to build a RAS directed to meet emerging demands, which require continuous and comprehensive assistance, not only focal and temporary, like the existing ones.

Due to the lack of studies that relate the functioning of a RAS to children with ZIKV, in addition to the particularities experienced by the mothers during the period of microcephaly diagnosis and treatment, data collection and research directed to the organization of the RAS in the context of endemic diseases will continue to be important for the academic environment and society, due to the need to reorganize all the nuances that make up the RAS, to guarantee the control of the disease in question.

As study limitations, the size of the study sample and the restrictions in the interviewees' speeches are highlighted. Thus, it is necessary to address this theme in other studies, to obtain more information and to sensitize professionals and managers about the problems found in the RAS that assist these children, in addition to encouraging the welcoming of these families.

It is also suggested that future studies related to ZIKV do not focus only on its biological and clinical aspects, but that they assist the services in building a service network capable of remedying the needs still left by the outbreak that occurred.

Conflict of interests: None declared.

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