

# CUIDADO É FUNDAMENTAL

Escola de Enfermagem Alfredo Pinto – UNIRIO

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## CONGENITAL ZIKA VÍRUS SYNDROME: “WE ARE JUST TOOLS, THE REAL THERAPIST IS THE FAMILY”

*Síndrome congênita do zika vírus: “somos só ferramentas, o verdadeiro terapeuta é a família”**Síndrome congénito del virus del Zika: “somos solo herramientas, el verdadero terapeuta es la familia”***Gleice Kelli Santana de Andrade**<sup>1</sup> **Sonia Silva Marcon**<sup>2</sup> **Júnior Cesar de Souza Benedito**<sup>3</sup> **Eliane Tatsch Neves**<sup>4</sup> **Sueli Mutsumi Tsukuda Ichisato**<sup>5</sup> **Elen Ferraz Teston**<sup>6</sup> 

### ABSTRACT

**Objective:** to find out how health professionals perceive the continuity of care for children with Congenital Zika Virus Syndrome in the home context. **Method:** a study with a qualitative approach was carried out based on the theoretical framework of Patient- and Family-Centered Care. **Results:** participants were 12 health professionals working in a specialized service in a capital in the Brazilian Midwest. It was found that the continuity of care for children with the syndrome in the home context is influenced by the insecurity of the unknown, fear of prejudice and family organization after the child's birth. **Conclusion:** health professionals seek to favor continuity of care, encouraging social interaction and children's independence and guiding families about their rights.

**KEYWORDS:** Child care; Child development; Health education; Microcephaly;

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## RESUMO

**Objetivo:** conhecer como os profissionais de saúde percebem a continuidade do cuidado às crianças com Síndrome Congênita do Zika vírus no contexto domiciliar. **Método:** estudo com abordagem qualitativa ancorado no referencial teórico do Cuidado Centrado no Paciente e na Família. **Resultados:** participaram 12 profissionais de saúde atuantes em um serviço especializado de uma capital do Centro-Oeste brasileiro. Verificou-se que a continuidade do cuidado às crianças com a síndrome no contexto domiciliar é influenciada pela insegurança do desconhecido, o receio do preconceito e pela organização familiar após o nascimento da criança. **Conclusão:** os profissionais de saúde buscam favorecer a continuidade do cuidado, incentivando o convívio social e a independência das crianças e orientam as famílias acerca de seus direitos.

**DESCRITORES:** Child care; Child development; Health education; Microcephaly;

## RESUMEN

**Objetivos:** conocer cómo los profesionales de la salud perciben la continuidad del cuidado de los niños con Síndrome Congénito del Virus Zika en el contexto domiciliario. **Método:** un estudio con enfoque cualitativo basado en el marco teórico de la Atención Centrada en el Paciente y la Familia. **Resultados:** los participantes fueron 12 profesionales de la salud que trabajan en un servicio especializado en una capital del Medio Oeste brasileño. Se constató que la continuidad del cuidado del niño con el síndrome en el contexto domiciliario está influenciada por la inseguridad a lo desconocido, el miedo al prejuicio y la organización familiar después del nacimiento del niño. **Conclusión:** los profesionales de la salud buscan favorecer la continuidad de los cuidados, fomentando la interacción social y la independencia de los niños y orientando a las familias sobre sus derechos.

**PALABRAS CLAVE:** Atención al niño; Desarrollo infantil; Educación para la salud; Microcefalia.

## INTRODUCTION

Brazil was the first country to identify the possible correlation between Zika virus infection and congenital malformation, and from the first cases in 2015 to October 2019, 3,474 confirmed cases of microcephaly related to ZIKV infection and other infectious etiologies have been reported.<sup>1,2</sup>

The affected children, in addition to microcephaly, also have other clinical manifestations, such as cognitive and motor deficits, epilepsy, dysphagia, changes in the visual and auditory systems, characterizing Congenital Zika Virus Syndrome (CZS).<sup>1</sup> Faced with limited knowledge about the course of the disease and treatment options, as well as the implications for the child and their family, health professionals and services have faced and still face a substantial challenge to meet the needs of children, while at the same time involving and supporting families as an indispensable component for the best development of the child, especially in the home environment.<sup>3</sup>

It is noteworthy that when families are guided to care for children with special health needs at home, positive responses are identified in their development and in the performance of basic daily activities, self-care and social inclusion. However, these interventions need to take into account the possibilities and limits of the main caregiver, the family and their support network.<sup>4</sup>

From this perspective, there are gaps in the care offered by professionals, with regard to establishing practical actions that adequately address not only all the needs of children with CZS, but also those exposed by their families.<sup>5</sup> Thus, health care for this population needs to extend to family-centered care, in view of their fundamental role in the continuity of care.<sup>6</sup>

This highlights the importance of health professionals working together with families, prioritizing the identification of problems related to the care of these children in order to maximize the quality and continuity of care in the home context. In addition, those involved in this process must be sensitized to qualified listening, to respecting the family's right to give their opinion and participate in decision-making, as well as having the support of the health system to provide comprehensive care.<sup>6</sup>

Given this context, the approach to care anchored in the assumptions of Patient and Family Centered Care (PCCF) has emerged as a promising possibility, as it has irrefutable advantages and substantial benefits for the patient and their family.<sup>4</sup> It is an approach based on mutually beneficial partnerships between patients, families and health professionals, and redefines relationships with an emphasis on collaboration at all levels of health care.<sup>7</sup>

Much has already been discussed in the literature about the epidemiology, diagnosis and clinical manifestations of CZS, however, long-term follow-up, as well as the repercussions beyond the health status of the child alone, need to be further explored.<sup>8</sup> Therefore, this study becomes relevant because it promotes discussions that involve comprehensive care for and with these families, as well as health professionals trained to have strategies that favor care in the home context, in accordance with the precepts of the PCCF.

In view of the above, the following question arose: what aspects favor or hinder the maintenance and continuity of care for children with Zika virus congenital syndrome in the home context. In order to answer this question, the aim of the study was to find out how health professionals perceive

the maintenance and continuity of care for children with Zika virus Congenital Syndrome in the home setting.

## METHOD

This is a descriptive-exploratory study with a qualitative approach, based on the PCCF theoretical framework.<sup>7</sup> The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to construct the study report.

The research was carried out in a specialized rehabilitation center located in a capital city in the central-western region of Brazil. It is a service that diagnoses, treats, grants, adapts and maintains assistive technology and has a multi-professional team.

Eligible participants were those with higher education who provided care to children with CZS and their families. Those who were unable to make an appointment after three attempts on different days and at different times were excluded. The interviews were terminated according to the criterion of sufficiency, when the number of interlocutors and the quality of their reports already allowed us to reflect the multiple dimensions of the object, based on the recurrence and complementarity of the information.<sup>9</sup>

The first stage consisted of searching the records contained in the rehabilitation service's electronic medical records system, in order to identify the health professionals working in direct care for this population. It should be noted that, during the data collection period, the institution had adopted a contingency plan due to the COVID-19 pandemic, so that specialty care was limited to a schedule of 50% of its total capacity, due to the reduced staff in the same proportion. Of the 30 eligible professionals, 15 were working in person (one doctor, one nurse, one nutritionist, one social worker, two psychologists, five physiotherapists and four occupational therapists).

The research was announced to the 15 professionals with the support of the supervisors of the professional categories, and all of them were personally invited by the researcher to take part in the study, with one not agreeing to take part and two not being available for the interview after three attempts to make an appointment. As a result, 12 health professionals were interviewed in a reserved room in the service itself, according to the participant's availability, but so as not to interfere with their work routine.

Data collection took place in September and October 2020, through semi-structured, audio-recorded interviews following a Free and Informed Consent Form (FICF). They were guided by a script with questions regarding the characterization of the participants, followed by the guiding question: tell me what aspects favor or hinder the maintenance and continuity of care for children with Congenital Zika Virus Syndrome in the home context. When necessary, support questions were used that addressed the following dimensions: feelings experienced by families that influence child care; factors involved in maintaining and continuing care in the Health Care Network; and

multiprofessional actions that favor the provision of care by the family at home.

The interviews lasted an average of 60 minutes and were conducted by the first author (a nurse studying for a master's degree in nursing with experience in qualitative research, who had no professional or social relationship with the participants).

In order to analyze the empirical material, the interviews were transcribed in full, preferably on the same day they were carried out, and were then subjected to the three stages proposed by thematic content analysis.<sup>10</sup> The pre-analysis stage involved systematizing ideas and organizing the material by reading the interviews thoroughly, identifying the core meanings and thematizing the data in the light of the study's objective. In the material exploration stage, by reading, classifying and aggregating the units of meaning, we then grouped them into identified thematic nuclei, which were: feelings experienced by the families; changes in family dynamics and the support network; needs of the child/family in the home environment; family health care; family participation in care; welcoming and supporting families; guidelines for caring for/stimulating the child and; resources for validating knowledge. In the stage of processing the results, two categories emerged from the articulation of the empirical data with the objective of the research, which will be described in this study.<sup>10</sup>

The results were interpreted and discussed in the light of the central assumptions of the PCCF: dignity and respect; information sharing; family participation in care and decision-making; and collaboration between patients, families, health professionals and managers in the development of public policies, professional education and research, as well as in the provision of care.<sup>7</sup>

All the participants signed the informed consent form, and to guarantee their anonymity the interviewees' statements were identified with the letter "P" followed by the numbering corresponding to the chronological order in which the interviews were carried out. All the protocols for preventing COVID-19 were adopted during the interviews.

The study was carried out in accordance with the ethical precepts set out in Resolution 466/2012 and approved by the Human Research Ethics Committee under opinion no. 4.133.629 and CAAE no. 30718620.2.0000.0021.

## RESULTS

Of the 12 health professionals under study, 11 were female, four of whom were physiotherapists, four occupational therapists, two psychologists, one social worker and one nutritionist. They were between 26 and 46 years old (average 35.6 years), had been trained for between three and 18 years (average 11.6 years) and had been working in the service for between 11 months and nine years (average 5.3 years). Ten of them said they had one or more specializations.

### Factors that influence the maintenance and continuity of care by the family

The participants pointed out that insecurity in the face of the unknown, fear of prejudice and difficulty in accepting and dealing with the situation mark the family context of children with SCZ, interfering in the way they are cared for:

*It was a child whose family didn't accept this diagnosis, that she had microcephaly, and her mother didn't accept it because she got pregnant and that child came, the only girl and she came special, and she said "my daughter won't walk? My daughter won't talk? My daughter won't sit down?" [...]. (P6)*

Furthermore, changes in family dynamics after birth, as well as the presence of a support network, were listed as elements that impact on the continuity and quality of care offered at home:

*[...] mainly the family structure itself, because it changes the family routine, often the mother ends up leaving work to dedicate herself to looking after the child and this causes financial problems, it causes problems in the marriage. (P1)*

Faced with the impact on those involved in caring for children with CZS, the interviewees confirmed the need for professional support focused on family health, as a resource that enhances the quality and continuity of care:

*I think that in general we have to take care of the family, because if they're well they'll be able to take good care of the child, and if they're not well even with themselves it's difficult to do the work of excellence with the children [...]. (P3)*

Another factor highlighted by the participants is the information that families have about the disease, which is sometimes considered insufficient:

*Sometimes the baby is born, stays in hospital, the family doesn't know why he was in hospital, they don't know what kind of care the child received and when you start to read the discharge letter to the family "gee, but did you have that?" [family], they didn't know, nobody said anything; so the lack of information, of health professionals seeing that person as a being participating in the life of that other being. (P1)*

In addition, the participants reported difficulties in establishing actions to encourage social interaction and independence for children with the syndrome at home, as they sometimes come up against overprotective families:

*We always ask them to "put it in the yard, put it on the balcony, wherever you leave it, let it have contact with other things" because children are always so overprotective "I'm not going to let anything happen because it will do more harm". And no, they need this contact with other family members too, it's important [...]. (P1)*

With regard to the resources needed to maintain care for children with CZS, the participants realize that families sometimes lack basic health needs:

*There are those whose families can't afford to eat or have the basics at home, so it's more complicated, because you know you need good nutrition for the child to be able to respond better. I mean this as a whole, both neurologically and physically. (P9)*

They also pointed out that some actions to stimulate the child's development are made impossible by the lack of adequate resources at home:

*The needs would be those related to adapting the house, having some kind of assistive technology; here we give orthoses, a chair, she has access through SUS, but there are other things that the mother ends up seeing the child's need for and she has to look for, other furniture, a feeding chair, [...]. (P8)*

Finally, it was emphasized that professional action requires guidance that shows the family that stimuli at home are essential if they are not to lose the progress made in therapy:

*The discharge process doesn't mean that he has stopped treatment. Often the treatment is for life. So if the family doesn't continue with this treatment, it can stagnate, it can get worse, they may not have a vision of improvement in relation to this patient, this person who needs this care. (P10)*

This category highlighted the factors that influence the maintenance and continuity of care by the family at home. In short, the continuity of care at home is marked by actions that include the role of the family in this process, co-responsibility for care and professional guidance that is unique to the socio-economic context of the families being cared for.

## DISCUSSION

Pregnancy is sometimes a time of social fulfillment, when the family makes plans and creates expectations around the arrival of a healthy baby.<sup>11-12</sup> Thus, facing the diagnosis of a chronic condition caused by CZS means facing a new reality.

In addition, these families face the scarcity of support services and the unpreparedness of society to receive/accept a child with CZS.<sup>13</sup> Consequently, the cumulative effect of all these feelings and experiences can weaken the family's mental health and directly affect their participation in care actions in the home environment.<sup>14</sup> There is evidence in the literature that these women go through a phase of emotional reorganization, and the fragility previously experienced is replaced by a feeling of strength, persistence and motivation for care.<sup>15</sup> Thus, in order to anticipate this transition, professionals can develop actions that encourage qualified listening and value family experiences.

It should be noted that the lack of information that families have about the disease is also an unfavorable element in the



process of caring for children. A study that analyzed the repercussions of the syndrome's diagnosis on families' lives found that mothers sometimes found out about their child's diagnosis by reading the declaration of live birth.<sup>12</sup> In addition, most families use information from the internet and social media.<sup>3</sup> In this sense, although CZS is a relatively recent phenomenon, and information regarding its natural history, prognosis and appropriate treatments remains limited, the role of health professionals in providing guidance on reliable sources and sharing useful, impartial and accurate information is reiterated, as a basis for positively influencing the family's effective participation in care.

On the other hand, the needs of these families include concrete aspects, such as the viability of resources to maintain care in the home environment, as pointed out in a study carried out in the capital of Pernambuco, among mothers of children with CZS, which pointed out the disproportionate way in which the disease affected the poorest populations concentrated in precarious urban areas.<sup>16</sup> These socio-economic disparities expose the level of socio-environmental inequality and reinforce the need for the government and public health authorities to formulate policies that address social determinants and promote the necessary social equity for this population.<sup>11,16</sup>

In addition, the importance of building horizontal relationships between health professionals and users of health services that guarantee them spaces for care and reception is highlighted.<sup>12</sup> In this context, the existence of activities to integrate and support these families for home care carried out at the institution was highlighted in this study.

An intervention study carried out with children diagnosed with CZS and their caregivers confirmed that these strategies provide participants with the opportunity to share information and exchange experiences, as well as recognizing their importance as caregivers and acquiring practical skills related to care.<sup>17</sup> It is therefore proposed that the multi-professional team welcomes these families through conversation circles and therapeutic support groups, as well as providing guidance to strengthen family participation in care planning and decision-making.

As this is a chronic condition, welcoming, respectful and transparent information given to the family about the state of health and prognosis favors the follow-up of care actions aimed at the quality of life of these children.<sup>18</sup> Although there is extensive and robust literature<sup>19-23</sup> revealing the value of family support in caring for children with chronic conditions, in practice there are many challenges to consolidating this co-responsibility in care. The family environment is a significant element in child development, especially for children with developmental delays.<sup>14</sup>

A study of children affected by CZS in the municipality of Recife found that children who were more stimulated at home responded better to postures and handling during activities, as well as interacting more with the environment around them.<sup>24</sup>

A study investigating mothers' perceptions of early stimulation and its repercussions on the development of children with microcephaly in the state of Ceará pointed out that the main negative point of the therapies was the short time spent with each

professional, which was considered insufficient.<sup>25</sup> Furthermore, in this relationship between the different health professionals and the family in the services that care for children with CZS, the bond and communication must be strengthened during all meetings. Furthermore, it is essential to promote the autonomy of this family, as well as to share responsibilities between them.<sup>6</sup> It should be noted that the transfer of responsibility for the care and monitoring of the living conditions and health of these children to specialized institutions and/or even to private health companies,<sup>26</sup> promotes ignorance and fragmentation of care demands, characterizing disease-centered care, as opposed to care in the light of the PCCF.

In the health care of children with CZS, there are countless barriers faced by families in terms of having the necessary resources to maintain care at home. They should receive guidance on how to find these resources, and clarification of the social rights guaranteed by law for this group.<sup>4</sup> At the same time, there is a desire to create public policies capable of supporting these children and their families,<sup>27</sup> and which can provide resources that fully subsidize the needs expressed by both. This lack of resources is reflected in the purchase of therapeutic equipment that enhances the child's neuro psychomotor stimulation at home.<sup>14</sup> This makes it necessary for families and health professionals to explore improvised ways of providing functionality similar to that which would be provided by the resources recommended by therapists, as these are often expensive resources on the health market and become inaccessible to the financial reality of families.

Among the strategies pointed out in this study to promote continuity of care, we added the use of educational interventions that use photographic records and videos as auxiliary tools to train families.

In short, maintaining stimuli at home will be crucial in order not to lose the progress made and avoid regression of the skills acquired by children with CZS. This concern arises because, in most cases, care for this population is limited and fragmented, in the face of a weakened network of care for children with chronic conditions, especially in Primary Health Care (PHC).<sup>8</sup>

This being the case, broader proposals for the production of care for this public are expected, including the importance of intersectoral actions and the formation of care networks for children with CZS, since they will need articulation between the social assistance, health and education sectors to ensure that they are welcomed and fully included.

## FINAL CONSIDERATIONS

Health professionals seek to promote the maintenance and continuity of care for children with congenital Zika virus syndrome in the home through strategies that address issues of insecurity in the face of the unknown and fear of prejudice. They share appropriate information, encouraging social interaction and the independence of these children through family integration and support activities.

Therefore, it is proposed that care be more closely linked to PHC, that spaces be created in which these families can care for

their children and themselves, that health teams be trained in order to expand professional listening, and that research, teaching and extension be encouraged to study this population.

The study's limitations include the impossibility of listening to all the members of the multi-professional team, especially the nurses. However, the findings of this study can support professional practice, especially in the field of nursing care, by revealing that therapeutic guidance provided by health professionals to the families of children with the syndrome offers conditions for their development at home, as well as supporting them in coping with the chronic condition.

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