

# Vulnerabilities and stresses of families of children with Congenital Zika Virus Syndrome\*


Vulnerabilidades e tensões de famílias de crianças com Síndrome Congênita do Zika vírus

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## ABSTRACT

**Objective:** to identify situations of vulnerability and accumulation of tensions in the care of the child with Congenital Zika Virus Syndrome. **Methods:** qualitative study, in which 40 mothers of children with Congenital Zika Virus Syndrome participated. The research instruments used were a semi-structured interview, construction of genograms and ecomaps and field diary notes. The collected data were submitted to content analysis in the thematic modality. **Results:** the main situations identified were caring alone for the child with Congenital Zika Virus Syndrome; conflicts with the partner or marital separation; family abandonment; absence or health problems with other children; and financial difficulties. **Conclusion:** vulnerabilities, family conflicts, and financial difficulties were considered sources of family tension and stress when facing expenses with medications and treatments, revealing racial and socioeconomic disparities in the access to health care.

**Descriptors:** Mothers; Microcephaly; Zika Virus Infection; Epidemics.

**Objetivo:** identificar situações de vulnerabilidade e acúmulo de tensões no cuidado da criança com Síndrome Congênita do Zika vírus. **Métodos:** estudo qualitativo, no qual participaram 40 mães de crianças com Síndrome Congênita do Zika vírus. Os instrumentos de pesquisa utilizados foram uma entrevista semiestruturada, construção de genogramas e ecomaps e anotações em diário de campo. Os dados coletados foram submetidos à análise de conteúdo na modalidade temática. **Resultados:** as principais situações identificadas foram: cuidar sozinha do(a) filho(a) com Síndrome Congênita do Zika vírus; conflitos com o companheiro ou separação conjugal; abandono familiar; ausência ou problemas de saúde com outros filhos; e dificuldades financeiras. **Conclusão:** foram consideradas fontes de tensão e estresse familiar as vulnerabilidades, os conflitos familiares e as dificuldades financeiras perante os gastos com medicamentos e tratamentos, revelando as disparidades raciais e socioeconômicas no acesso à saúde.

**Descritores:** Mães; Microcefalia; Infecção por Zika Virus; Epidemias.

## Introduction

During the years 2015 and 2016, the infection by Zika virus (ZIKV) in the gestational period brought visibility to the cases of Congenital Zika Virus Syndrome (CZVS), in Brazil, in which the Northeast, especially, became known by the epidemic of CZVS, highlighting Pernambuco and Paraíba as the states that had the highest concentration of cases<sup>(1)</sup>.

With the confirmation of the CZVS and the improbabilities surrounding its prognosis, indicators of anxiety and depression are pointed out as aggravating factors of physical and psychological vulnerability<sup>(2)</sup>, in which a process of adaptation and acceptance in the life of the mother and family members is initiated. In this sense, vulnerability is understood as a fragile interpersonal and family organization circumstance and is determined by the accumulation of functions that are no longer performed or of demands related to the family unit. The greater the accumulation of unfulfilled functions, the more vulnerable the family becomes and, depending on the family cycle in which it is inserted, it may be exposed to even greater levels of tension<sup>(3)</sup>.

Thus, because it is a group of children with disabilities and chronic conditions, the image of maternal abnegation appears strong in the context of excessive frailty and denial of rights<sup>(4)</sup>, considered the factors that interfere in the adaptation process<sup>(3)</sup>.

In face of the difficulties faced in the daily life with the child with CZVS, the concern with the accumulation of demands required by CZVS raised the need to answer the question: "Which situations have been considered tension generators and contributed to the vulnerability of mothers and their families in the care with Congenital Zika Virus Syndrome? Thus, it was aimed to identify situations of vulnerability and accumulation of tensions in the care of the child with Congenital Zika Virus Syndrome.

## Methods

This is a qualitative study with interpretative research, carried out according to the criteria recommended by the Consolidated Criteria for Reporting Qualitative Studies (COREQ) and based on the Resilience, Stress, Adjustment and Adaptation Model<sup>(3)</sup>, which allows the identification of the families' potentialities to deal with stress, as well as the adaptation process in response to a crisis-generating situation.

The study was developed in a Specialized Rehabilitation Center, located in the interior of the State of Paraíba, a reference in the care of children with CZVS, in which approximately 100 children with CZVS from the State of Paraíba were registered

During data collection, 48 mothers who were with their children in care were randomly invited. Of these, two showed no interest in participating, one of them because she had already participated in other research studies with long questioning; in a single situation, there was a mismatch between the researcher and the participant, when she said she preferred to leave the interview for another opportunity, which did not happen. Another five women were excluded because they did not meet the inclusion criteria: two of them were not the mothers of the children in care and three reported not having confirmation that the diagnosis of their children was associated with ZIKV.

Thus, 40 mothers of children with CZVS from different municipalities of the State of Paraíba, affected by ZIKV during pregnancy (confirmed by laboratory tests) participated in the study. Mothers of children diagnosed with microcephaly associated with other infection(s) were excluded.

Data collection occurred from June to November 2017. The interviews were conducted in a private environment, at the Specialized Rehabilitation Center, ensuring the privacy of the researcher and interviewees. Before granting the interviews, the participants

were informed about the objectives of the study and the importance of their participation. The Informed Consent Form was read by the researcher and signed by the participants and, only after this moment, data collection began.

For the interviews, a semi-structured script developed by the researcher was used, with closed and open questions, contemplating the different phases of the adaptation and resilience process, associated with the construction of the genogram and the ecomap, thus expanding the understanding of the context of each family and the relationships established among its members. As a complement, notes were taken in a field diary.

The genogram is considered a potential standardized instrument for family assessment through a graphic representation, in which pre-defined symbols and codes are used to help understand the family conjuncture of several generations<sup>(5)</sup>. The ecomap, also, is considered a potential instrument of family approach that allows showing the resources that the family presents at that moment, the quality of their bonds and their relationships<sup>(6)</sup>.

To facilitate the process of obtaining narratives, the questions and answers were recorded with the aid of a portable digital recorder, ensuring confidentiality as a priority. The final sample was determined by theoretical saturation when the information reached became redundant. The average duration of the interviews was 20 minutes and 47 seconds, totaling 819 minutes and 11 seconds.

The answers were transcribed in full. For the organization and analysis of data, the MAXQDA® software, version 2018, was used and a categorization of codes was established, with their respective definitions discussed and reviewed by the researchers, seeking to adjust them to the theoretical precepts of the referential, allowing validation. The transcribed data were tabulated and then proceeded to the construction of categories directly, based on the theoretical framework and following the Content Analysis technique in thematic mode<sup>(7)</sup>.

The mothers' names were replaced by the letter M followed by a sequential number. Similarly, the names of other children, as well as clinics and hospitals were replaced by sequential letters as they appeared, and the name of the child with CZVS was replaced by the letter C (for child) followed by a sequential number. The mother's and child's numbers did not always coincide, as three mothers of twins participated in the research.

This study was approved by the Research Ethics Committee of the Federal University of Campina Grande under Opinion number 2,118,518/2017 and meets the norms and guidelines for research involving human beings.

## Results

The age of the mothers ranged from 18 to 39 years, with a mean age of 26.6 years. Regarding race, 31 (77.5%) said they were black, five (12.5%) said they were white, three (7.5%) said they were yellow, and one (2.5%) did not know how to specify. 33 women (82.5%) were housewives, 21 (52.5%) of the families earned between one thousand and one and two thousand reais, 16 (40%) families earned less than one thousand reais, and only three families (7.5%) earned between two thousand and one and three thousand Brazilian Reais.

The main situations identified in the study were: caring alone for the child with CZVS; conflicts with the partner or marital separation; family abandonment; absence or health problems with other children; and financial difficulties.

Some women-mothers showed fragility in the care of their children, contributing to the overload of work and responsibilities. Of the 40 interviewees, 10 said that they raise their children alone: *I take care of her, only myself. He works, but he only works, he does not give her water, milk, he does not do anything. He only takes her a little bit. He walks, goes for walks, goes to church and I do not go anywhere (M4). Woman, I am a widow! His father died three months ago. I had to take him (another son) out of school because there was no one to take him*

(M19). *Woman, when he has, he gives me, but it is 20 reais. He does not even ask about the boy and does not even ask to see him* (M34).

Conflicts with partners were identified as stressful factors by some mothers: *So, he helps, he understands, but sometimes, when I need him the most, he is not in time to help me, he disappears, he argues. Before we did not fight, today we fight... We have never fought in six years. Since a year and a half, we only fight...* (M2). *When he disappears from my life once and for all, and does not show up at my door, I will go to court, because until today he has not even given him a can of milk, and the other two I do not even know where he lives... He does not help at all, that is why I do not want him to show up at my door* (M9).

The issue of abandonment by the partner and the marital separation in such a fragile moment also appeared recurrently, which could harm the adaptation process: *I do not live with his father. Then, when I found out I was pregnant, I went to tell him, he said it was not his child, he said he would not register the child, and I said: that is right. So, I registered it only in my name, then I went to court, then it was proven that he was the father, but he never paid attention to the boy, no* (M3). *As "B" is special, he accepted it for 2, 3 months, then he disappeared... The most difficult moment for me was the absence of the father, when I came home from hospital A, the first day I came home, he was not there to receive me at home. I stayed 2 days in my house when I came home from hospital A, and he did not come there to visit me...* (M34). *The only thing that I found strange was just her father, which I thought was going to be a thing, right? How do you say, I thought I was going to have more support* (M36).

For M26, who got pregnant by a stranger during a party after getting drunk, her conflict involved the whole family, since her parents did not accept it and she was kicked out of the house. She built a two-room house with a small amount of money she received from her ex-husband in the divorce proceedings and lives with her two daughters, showing several weaknesses. M26 also reported feeling helpless and suffering a lot with the situation: *My family does not care about me because I had her. They abandoned me, they live nearby, but, when I go to talk, they come with four stones in their hands... After I got pregnant, I had left and when I got home, she (mother) had thrown my clothes, everything, she said she did not want me in the house anymore, so I spent three months in the neighbor's house.*

*Then I managed to build this house with the money I earned* (M26).

Besides the family conflicts through the construction of genograms and ecomaps, it was possible to validate the data presented, and it was observed the separation of other children living with relatives, usually grandparents, in an attempt for the mother to have participation in the care of the child with CZVS that requires differentiated care.

With the overload, the mothers showed concern about not being able to give attention to other children, and how this has been an accumulation of tension for them, which generates a feeling of weakness in the way of raising and educating, in addition to the siblings' own demands: *He doesn't even call me mother, my mother is the one he calls "mainha" (an affectionate way to call one's mother in the Northeast region of Brazil)* (M1). *It changed a lot for me, that I have a daughter, I do not have time for her, she keeps complaining* (M16). *I do not even have time sometimes for my other daughter* (M7).

One of the mothers even recognized that she was making mistakes in the way she raised her son, and even commented that she was "spoiling" her son, because she has been replacing his presence with material goods, in an attempt to compensate for his absence: *For me, I feel that I am spoiling my son, the other one, because, as I come to Campina a lot, I go out a lot with him, I leave the cell phone and everything he wants I give him, to try to compensate for what I miss, you know? He asks to play with his cousins, whenever he wants, I let him, then I see that I am spoiling him, because, when I say 'no' to him, he does not want to accept it, then he starts to yell at me, argue, then I say that I am spoiling him* (M15).

Considering the challenges faced, it is also noted that health problems with other children are among the factors that contributed to the accumulation of tensions in families, favoring vulnerability: *He started treatment when he was 2 years and 2 months old... He was very withdrawn, so I started incredibly early. I have been to "B" (support home for autistic people), I have been to Psychosocial Care Center, I have been to Hospital B, which has a psych pedagogue there, then he came here, and his therapies increased.* (Talking about his older son, who is autistic) (M6). *The one that I break my head a lot is the other, the 8-year-old, I think he is hyperactive, he is too crazy,*

he hits the other 5-year-old a lot, if I do not remove him, he kills her (M11). The other one has a little problem; she takes controlled medication. I am still waiting to do an MRI, even her papers are here (M22).

Based on the narrative, Figure 1 shows the genogram and ecomap of the family six that, besides the child with CZVS, the couple has a son with autism.

Regarding treatments, they attend the specialized rehabilitation center three times a week, two days for the children and one day for psychological follow-up of M6. Once a week the child with CZVS is accompanied in a philanthropic institute. Thus, the instrument reveals its importance for the construction of the demands and vulnerabilities found in each family.

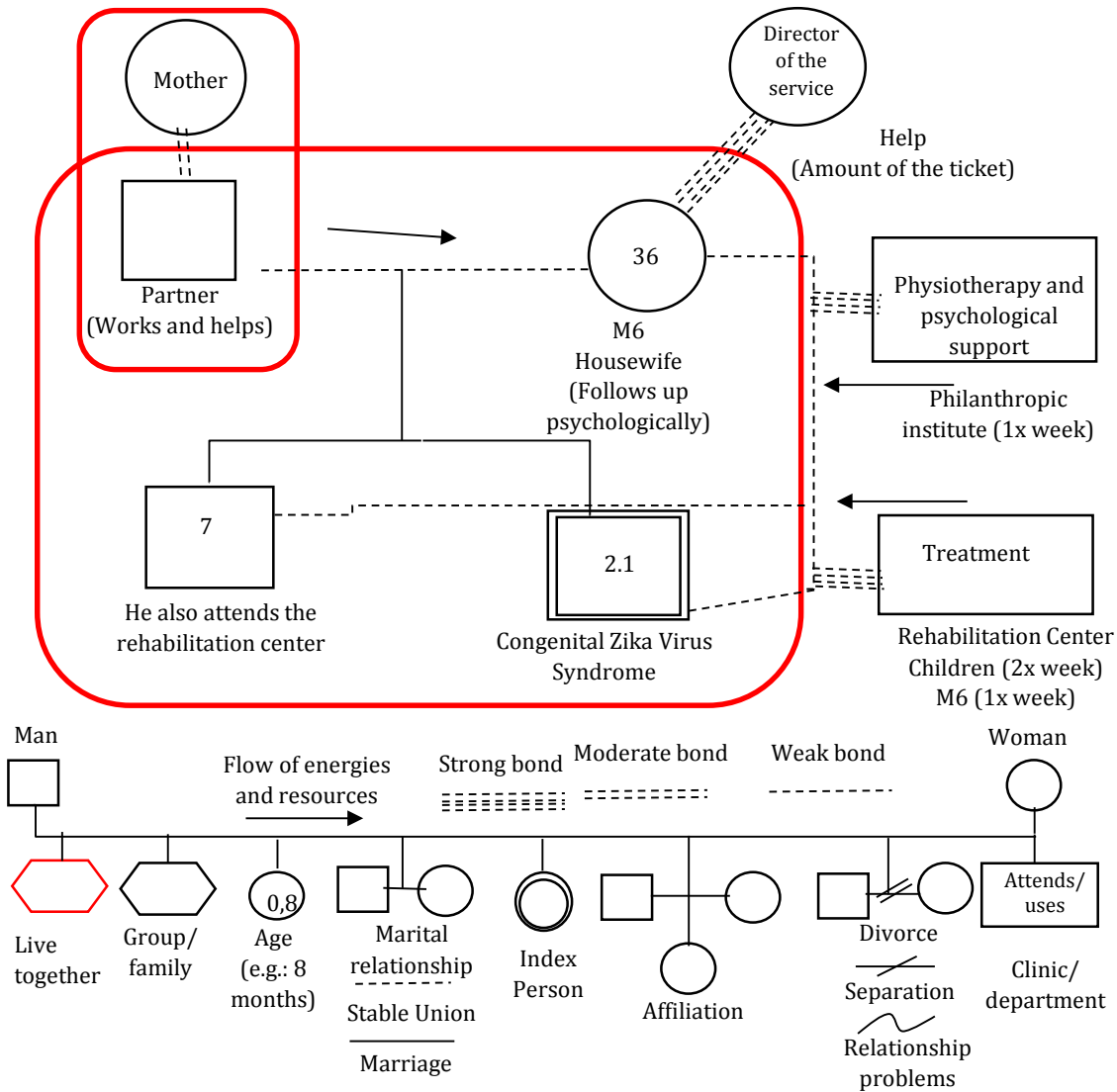


Figure 1 – Genogram and ecomap of family six. Campina Grande, PB, Brazil, 2017

One of these mothers reported having planned her pregnancy in the hope of having a healthy child to know what it would be like to be the mother of a normal child, and her son was born with CZVS, further aggravating the issue of overload: *I don't know if it was punishment, because when I planned to get pregnant with C8's brother, I didn't think of having another special child, I only thought that he would be perfect in health to have the lesson, the responsibility together with me to take care of C8. But then, everything was the other way around... And God showed me that it was not the way I wanted, no* (M6).

Coupled with these problems, the previously existing financial difficulties are added, mothers who stopped working to fully dedicate to the child, as well as the partner's unemployment, thus increasing the other existing stressful factors, which came to represent a family vulnerability: *His money is only enough for his expenses, there is 200.00 reais left, but you cannot do anything with 200 reais. The expense is big, plus the exams and the debts with credit cards, because, at the time that C8's brother was born, I did a lot of exams (talking about his partner's salary)* (M6). *I am at a dead end, because what she is earning is 930 reais, so I keep borrowing money from loan sharks to cover it, in fact my life has turned into a big snowball, hasn't it?* (M14). *I already asked for alms for my daughter, can you believe it? Because when I had her, I only had her and 70 reais from the Bolsa Familia* (M26).

Thus, it is noteworthy that many are the demands and challenges faced by mothers of children with some type of special need in our society. The fact of having a child with CZVS in itself is already a factor of great vulnerability, as it implies spending more time and attention, often requiring changes in the family routine, in addition to greater financial responsibilities.

## Discussion

main limitations found in the study are related to the fact that the collection was developed in a single outpatient health service that attends to several disabilities, as well as the fact that the interviews were only with the mothers of the children. Listening

to other mothers, families and companions could have shown different realities and outcomes, as well as meeting families of children affected by CZVS who were not receiving assistance due to different factors and of those who did not survive the tragedy.

Identifying the vulnerabilities and accumulations of family tensions and recognizing the implications for the woman caregiver and the family unit may collaborate with the qualification of the assistance of health professionals who deal directly with these mothers and children, reinforcing the need for actions to give visibility to the context, promoting discussion, mobilization, and struggles for the realization of human and social rights in the CZVS.

The changes coming from caring for a child diagnosed with CZVS have involved "emotional, social, spiritual, and economic aspects, as well as a process of transformation and suffering"<sup>(8:7)</sup> and, by bringing to light the changes occurring in the lives of mothers, have unveiled the presence of many neglected issues, having disproportionately affected women, particularly those from vulnerable families who also need care.

The challenges of the CZVS are marked by emotional overload and physical exhaustion<sup>(9)</sup>, among which the mothers in this study highlighted the difficulty of caring for their children alone. In this context, the mother becomes the only or main caregiver, which already requires attention, and from then on, she starts to live almost exclusively for the child, adding to these functions that of the main responsible for the organization of the family and children's routine<sup>(10-11)</sup>. This public image of the role of motherhood and responsibility imposed by parenthood and attributed to the mother brings to light issues of gender inequalities prior to the pandemic.

Women who, many times, before the birth of a child with CZVS end up getting into conflicts or even being abandoned by their partners<sup>(12)</sup>, having their own maternal overload as a contributing factor to the separation<sup>(9)</sup>. In this sense, the support of the spouse and family members, friends, and community organi-

zations are reliable sources of emotional and functional assistance<sup>(13)</sup>, as well as active listening is an important source of support for coexistence and care of the child<sup>(14)</sup>.

In a study carried out with parents and family members of infants and children with CZVS, family support was also restricted or even absent<sup>(15)</sup>. In Alagoas, Paraíba and Pernambuco, deficiencies related to social support from family members and from the partner were also observed, and it was verified that some fathers did not remain with their partners after the diagnosis, as well as were not participatory in the process of childcare, further aggravating the vulnerability of these mothers. Even when fathers assumed paternity, they did so with feelings of disbelief about the prognosis<sup>(10)</sup>.

It is noteworthy that lasting social bonds are important for coping and overcoming moments of crisis<sup>(9)</sup>, however, it has been observed that mothers of children with CZVS endure difficulties in the marital relationship, in the family and social context<sup>(16)</sup>. Doctors who provide care to patients with microcephaly emphasize that men have more difficulties than women to accept the disability of their children<sup>(17)</sup>.

In the United States and around the world, families of children with developmental disabilities also face similar challenges and need emotional and functional support and information to understand and address their child's special needs, which can be obtained both through professionals and the community<sup>(13)</sup>.

With the disease, the affective ambivalence experienced by the mother in her entire being is accentuated due to the relationship with a child who will demand even more care and assistance due to the loss of autonomy. Thus, the intense routine of childcare generates new vulnerabilities that can directly affect the mental health and quality of life of this mother and her family<sup>(10)</sup>.

One element that drew attention in this study was the presence of the affection for different health problems in other children. As well as three pregnan-

cies of twins, in which two children were born with CZVS, which implies a specific maternal assistance added to the need to organize themselves to provide care and therapeutic itinerary for more than one child, which aggravates the vulnerability of that family nucleus due to the abandonment or insufficient care to the other children.

As for the limitations imposed by the multiple demands of the CZVS in case of more than one child, the evolutionary changes are also a difficult task for both the mother and the firstborn, who ceases to be an only child. Thus, the mother often becomes less sensitive to the child's needs, which does not mean that there is a decrease in maternal attention to the child. A study carried out with siblings of children in chronic conditions pointed out that they, too, appeared in a situation of vulnerability and exclusion regarding care, with difficulties in dealing with their perceptions and feelings<sup>(18)</sup>.

Regarding rights, women, and children with CZVS continue without the guarantee of social rights<sup>(1)</sup>. The financial difficulties by themselves already imply possible causes of family conflicts, accentuated with the disease due to the increase in expenses and, even with family aids such as the municipal free pass and the continued benefit, many mothers complained that the amount received was scarce for the expenses with the child, further compromising the family income and limiting their quality of life and that of the children affected. Another recurring complaint was that, when registering for the benefit, they and their partners were not allowed to have formal jobs with a formal contract, generating indignation.

None of the mothers of children with CZVS were protected by the continued benefit in 2016 and, among the few who enrolled, none of them was summoned for the social expertise<sup>(19)</sup>. With this study, a positive change was observed in the sense that, despite considering it insufficient of the 40 mothers, only, six did not compute the receipt of the benefit.

In a study conducted in the Northeast about care from the perspective of mothers of babies with

microcephaly, the participants stated that the main or only help they received was the continued benefit, coinciding with this study, confirming the strong relationship between social vulnerability and the ZIKV epidemic<sup>(10)</sup> that produces new precariousness due to the existing social inequality<sup>(19)</sup>.

In view of these demands identified in the care of the child with CZVS, mothers become penalized by the lack of guarantee of an organized attention network, as well as the absence of rights for people with disabilities<sup>(4)</sup>, compromising the integral care of families with this condition, generating more inequity in society, due to the irresponsibility of the State. Confronting with the theory, the situations found in the study indicate disorganization, interruption and imbalance in the established patterns that are considered generators of family crisis<sup>(3)</sup>.

Considering the vulnerabilities and tensions present, it is necessary to develop care proposals that contemplate the mothers and their families, understanding their particularities and envisioning individualized ways of offering care and assistance. It is hoped that the results of the research can guide the idealization of new political proposals, orientation, and approach programs for similar health situations in other families.

## Conclusion

The study allowed identifying situations of vulnerabilities and accumulation of tensions in the care of the child with Congenital Zika Virus Syndrome, revealing that family conflicts, regardless of resulting in abandonment or separation from the partner, are sources of tension and allow recognizing the strength of these mothers in taking care of their children practically alone, because most of the time they have other children who need their care. Added to these stressors are the financial difficulties, since, regardless of the receipt of the continued benefit, it is still considered scarce in the face of spending on medicines and treatments, revealing the racial and socioeconomic disparities in access to health.

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## Collaborations

Hamad GBNZ contributed to the conception and design, data analysis and interpretation, writing of the article, relevant critical review of the intellectual content, and final approval of the version to be published. Tupinambás U and Souza KV contributed to the writing of the article, relevant critical review of the intellectual content, and final approval of the version to be published.

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