

## Family restructuring in the context of baby's care with Zika Virus Congenital Syndrome

Reorganizações familiares no contexto do cuidado ao bebê com Síndrome Congênita do Zika Vírus (resumo: p. 17)

Reorganizaciones familiares en el contexto del cuidado al bebé con síndrome del Zika Virus (resumen: p. 17)

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This paper addresses family members' experiences in the care of children with the Zika Virus Congenital Syndrome. It aims to analyze the impact of the birth of babies with malformations, the parents' psychological restructuring – especially the mothers' – and the implications in the baby's care. A psychosocial, psychoanalytical approach was adopted in dialogue with Public Health studies. We analyzed the narratives of family members who attended 32 group meetings conducted in an outpatient clinic of a Research Institute in Rio de Janeiro, Brazil, in 2017. The analysis was based on psychosociology and thematic analysis. Anguish, uncertainties, and overload marked parental experience. The baby's developmental difficulties led parents to a unique way of dealing with their children and building hope and resistance paths. Maternal leadership became the basis for struggles in the social, health, and education fields.

**Keywords:** Zika virus. Disability. Care. Motherhood. Family.



## Introduction

In 2015, the Zika virus epidemic in Brazil was recognized internationally as a significant emerging public health problem, given the evidence of this virus as a cause of fetal malformations in the gestational period, with severe effects on the fetus' central nervous system, especially microcephaly<sup>1-4</sup>. This condition was later called Zika Virus Congenital Syndrome (ZVCS) and demanded a wide range of clinical and epidemiological studies and studies on its social and human consequences.

Babies with ZVCS had microcephaly or other neurological disorders and possibly brain calcifications, epilepsy, hearing and visual impairments, and psychomotor development delays<sup>5</sup>, resulting in a chronic health condition that comprises continuous physical and structural disabilities. As they demand daily arrangements for elaborating new life forms, such illnesses are fragilizing experiences and generate family suffering. The vulnerability experienced by relatives of babies with ZVCS combines difficulties in accessing income, weaknesses in affective and social bonds, and living with stigma and unequal access to public goods and services, with long-term social and economic repercussions<sup>6</sup>.

Like all human reproduction-related issues, gender played an important role in the impacts and responsibilities in the Zika virus epidemic, imposing dramatic consequences on women, involving pregnancy, the baby's birth, its diagnosis, and treatment<sup>1-3</sup>. The epidemic showed an impacting scenario, with the birth of children with unknown health needs and the pilgrimage of families seeking health services, which notably led mothers to a fight for rights before the State<sup>7</sup>.

In the face of the epidemic, different public institutions turned to developing clinical research and providing care to children and their families. In this context, a line of Zika care and studies was developed in a research institute in Rio de Janeiro, Brazil. The research "Psychosocial Implications of the Zika Virus Congenital Syndrome (ZVCS): the experience of relatives in caring for children with neurological disorders from a group device" was conducted and aimed to support family members by offering a space for sharing the emotional experience of their babies' illness and investigating the consequences of ZVCS for parenting and family care. The theoretical framework was guided by a psychoanalytical psychosocial approach with an interdisciplinary perspective, articulating the psychic record and the social reality and its determinations in individual stories<sup>8,9</sup>, in dialogue with Public Health studies related to the Zika virus epidemic. This paper is an excerpt from this larger research and targets the baby's and family care experiences' subjective effects. It aims to study the impact of the birth of babies with malformation, parental psychic reorganizations, and consequences on care, particularly maternal care.



## Methods

The research was carried out from March to December 2017 in an outpatient clinic of a research institute geared to pediatric care for children with ZVCS. The study period was a critical moment in the epidemic, in which most babies were less than one year old, in a context of scarce scientific information and preliminary design of specific public policies.

The investigation was developed through a one-hour group meeting held every week and open to mothers, parents, and other relatives of the children attended at the pediatric outpatient clinic geared to Zika. They were invited to participate in the group in a room close to the offices while waiting for medical care. All those willing to participate were included as research subjects.

The authors conducted the groups, and one of them was a member of the clinical team. The dual belonging of one of the authors was clear to the participants. The researcher must consider such an issue from the viewpoint of the psychosociological approach, and must be aware of the subject's idea of him and its implication.

Based on recognizing the situation of vulnerability imposed by illness, we aimed to provide a space for receiving and listening to the subjects and, simultaneously, producing knowledge about their experiences of caring for babies with ZVCS. We intended to support family members with the group space, favoring the expression of their narratives, the exchange of experiences, and the individual and collective elaboration of their experiences with their children.

The methodology was based on the clinical, qualitative perspective<sup>10</sup>, particularly the French clinical-psychosociological approach. Such an approach is anchored in the understanding of the clinical device simultaneously as research and psychosociological intervention<sup>8,11</sup>. Therefore, we understand that the construction of group narratives leads its participants to share their pain and apprehend and symbolize the situations in which they are involved. The psychoanalytic orientation provided an understanding of the group as a place to look closely at the subjects and a field of mediation, recognition, support, and continence of subjective and psychosocial experiences<sup>12,13</sup>. The coordinators were guided by an active clinical stance in tune with the participants' modulations, encouraging sharing individual experiences and recognizing difficulties and impasses, but highlighting that there were also group processes of coping with the illness situation.

Thirty-two group meetings were held. Two meetings were staged in the ward due to many babies with ZVCS hospitalized at any given time. While hospitalization is a more tense moment for relatives, mothers showed much interest in group meetings and brought dense narratives of their care course.

It is important to note that the context of the epidemic was also accompanied by an overload on families regarding the demands for participation in research and this situation was also found in the clinic where we developed our work. This study provided simultaneous support to the subjects through the adopted methodology.

The groups began with a presentation of their proposal: as a space for talking and listening to the experience of relatives from the diagnosis of Zika; and as a research space, presenting its objectives and the Informed Consent Form. We also informed that psychology professionals could monitor relatives and had guaranteed their



presence in the group, regardless of their participation in the research. We used a question that could trigger the narratives to start the group; in the first months, it was: "You are bringing your children with Zika to receive care. What was this experience like for each one of you?". Later, with the presence of older babies, we modified the questions a little, as follows: "How is this moment of child care? What are your concerns at the moment?". All group meetings were recorded and later transcribed.

Throughout this period, 59 families participated in the groups, totaling 86 relatives, including mothers, fathers, grandparents, and uncles. It is worth mentioning that most caregivers were mothers, representing 64% of the total number of participations, with grandmothers and fathers sharing the same percentage level of 15%. Most families lived in suburban areas of the city and other municipalities in the state. They had low schooling and more than one child. The maternal role in caring for the child with ZVCS, as a way of experiencing parenting, in which the mother-child dyad predominates<sup>7</sup>, was expressed in the narratives and analysis developed here. Other studies on Zika or other chronic illnesses highlight the fundamental gender issue<sup>5</sup>.

The analysis process was based on the psychosociological perspective<sup>8,9,11</sup> and the thematic analysis<sup>14</sup>. It built on the empirical material's active listening work, through a free-floating reading of the groups' transcripts, allowing a work of association, construction of meaning, and identification of thematic units, in dialogue with the literature, which facilitated the construction of axes and analytical categories.

The primary research was based on three analytical axes: parenting, family and social support network, and care practices in health services. This paper focuses on the first axis of analysis and aims to understand suffering, parental reorganizations, and their experiences in caring for babies. It was organized around three main categories: (i) parenting, baby malformation, and trauma; (ii) bond and affection: parental psychic reorganizations; (iii) care: maternal role, overload, and adaptation.

The study fully met the ethical requirements of Resolution N° 466/CNS/12, and was approved under CAAE N° 60221416.7.0000.5269. All family names are fictitious. At the end of the research, we held a meeting with relatives to present and discuss the results.



## Results and discussion

### Parenting, baby malformation, and trauma

Parenting can be understood as a process of building the parent-child relationship from a set of representations and affections of parents vis-à-vis their baby, which becomes especially the object of their subjective work during pregnancy<sup>15-17</sup>. There is then a work to prepare the relationship with the baby, from which the imaginary cradle in which he will be received will be established, full of dreams and future aspirations.

The news of the malformation establishes a crisis, a “fracture” in the ideal represented by the baby, causing a great shock and an extensive process of parental psychic reorganization. The birth of a malformed baby represents contact with an unknown world, with something unrepresentable, in such a way that we could say that “things remain suspended. Nothing supports the situation [...]. It is this hole that traumatizes”<sup>18</sup> (p. 50).

A striking axis in the parental narrative is precisely the traumatic experience of shock and awe triggered by the diagnosis and the baby's encounter; some parents say they feel helpless.

When I found out, I cried a lot. When the exam confirmed that he would have microcephaly. [...] We thought he would be a transient thing, that he would return to normal. However, it just got worse. (Citrino, father)

We've been trying for a year. [...] He is our first child. [...] I had no diagnosis during prenatal care. A different image appeared in the last ultrasound. It was the beginning of Zika. They failed to define. When he was born, the pediatrician found that his head was smaller, which was a saga. (Nácar, mother)

The encounter with the baby was a moment feared by mothers as it stirred anguishes related to a body image that portrays the malformation:

As I knew a week before, it was a long week! Out of total despair, until he was born. It wasn't about not accepting. I think it was the fear of seeing. (Turqueza, mother)

The mother is faced with the baby's body, with its difference, as a risk, configuring what Aulagnier called “encounter trauma”<sup>19</sup> (p. 41). The trauma refers to a hole in the symbolic order; an excess, something that breaks out and breaks the sense of continuity of the being, generating a breach in reliability, which can bring an experience of the “meaningless”<sup>20</sup>.

In the case of Zika, uncertainties and lack of knowledge of the disease and its effects were markedly experienced in the first year of the epidemic, both by family members and health professionals, increasing family suffering.



The social context increased parental fears and potentiated the effects of the traumatic encounter with the baby, as it anticipated fears about his/her future and how he/she would be accepted socially. At the time of the onset of the epidemic and the discovery of the relationship between microcephaly and the Zika virus, the media carried news and images that reinforced fear and uncertainty for family members and even referred to babies in a disqualifying way<sup>21</sup>. Health authorities also referred to babies violently, calling them “a sequelae generation”<sup>22</sup> or “lost generation”, highlighting ethical issues and state violence<sup>21</sup>. This context reinforced parental anxieties:

Then I saw [on TV] those frail children, who would not be able to do anything, vegetating. (Jaspe, mother)

According to Diniz<sup>21</sup>, the use of the dehumanizing “vegetable” metaphor was used by doctors to refer to babies. It is disrespectful and offensive to parents. The experiences of loss heightened by child malformation since birth is a public event and the fractured ideal that the child represents affects the family network and the experience of being a father and mother in society<sup>23</sup>, corresponding to a social recognition denial experience<sup>24</sup>. The psychosocial fragility is manifested then through the lack of social support and stigmatizing behaviors that disqualify the child and his family, instilling in parents fears about the future.

### **Bond and affection: parental psychic reorganizations**

Creating a humanizing bond, making the baby your child, implies building a shared story in which the otherness component is present<sup>25</sup>:

In fact, in the beginning, I think that for any parent, it is difficult to accept that their child has microcephaly or hydrocephalus. In the beginning, with the first blow, the reaction is to deny, to reject. “He doesn’t have it” [...] (Peridoto, father)

Psychic parental work is hard. It requires time to overcome the trauma and build affective investment and bond with the real baby<sup>26</sup>. As suggested by Gomes and Piccinini<sup>23</sup> in their study on malformation and motherhood, mothers feel that:

such terror will not end. So much despair, helplessness, and powerlessness in the face of the long road ahead, treatments... and worst of all, fears, uncertainties, and impending death<sup>23</sup>. (p. 27)

There is much dedication, but also ambivalence, in the sense of the existence of contradictory and antagonistic effects:

It makes you want to give up. When I was hospitalized, I wanted to leave. I already went downstairs. I walked on the shore of this beach. But I thought, “I have to go back. If I don’t have the patience, who will?” (Âmbar, mother)



At first, you get terrified [...] we took a hit; we were sad... we go rock bottom... but then again, we had to go through this to see that he needed us to achieve some things. (Fluorita, mother)

There is a subjective, initially strange work of transforming the baby into a family member. The mother's adjustment effort will allow her to establish contact with the baby's emotional state<sup>27,28</sup>. From the affective investment in their son's particularities, some parents showed that he was both an object of care and recognized in his singularities. Mothers considered their baby's sensitivity and unique tastes:

He likes massage... I massage him every day... He asks for a massage... His hand opens... He relaxes... [...] It seems that we already understand his way when he is satisfied. (Diamante, mom)

She pays attention when a bird is singing [...] when someone is laughing. I went to the bank. She started laughing, participating in someone else's conversation! It was hilarious! (Calcita, mother)

The narratives also indicated another repercussion in the subjective maternal position: extreme maternal involvement, hindering any baby distancing. Children in serious situations demand more care and trigger intense anxieties in their mothers, which can lead to excessive involvement and responsibility:

She was hospitalized [...] for me to have a meal down there ... I don't leave my daughter alone. So, when no one came [another relative], I was left without a meal. I had to count on a cookie. (Jaspe, mother)

While maternal overprotection can be adaptive and zealous protection, to some extent necessary for the child, it can also be understood otherwise:

It is as if his [the baby's] vulnerability was always an open door to more tragedies, which could, fantastically, be avoided by her excessively protective posture<sup>29</sup>. (p. 23)

Another situation of a baby that is also severe is emblematic of the presence of selfless motherly love. In this case, issues arising from the weak family and social network made the situation dramatic:





I've been here for four months. My son was hospitalized. He had to go to the Severe Patients Unit. He was intubated [...] I have a younger baby. [...]. The baby stays with a different person every day [...] I cannot even take care of my four-month-old son. I'm looking for daycare. [...] And I have two daughters aged 9 and 12. The latter is at home alone, and the former is with her father. (Safira, mother)

This fragment portrays an experience of family fragility, with massive affective investment directed at the sick child, hindering care for other children. In these situations, parental reorganizations articulated subjective processes, and socially vulnerable contexts were also identified in other studies on Zika, in which motherhood is associated with the tireless struggle for the sick child<sup>7</sup> and the radical change in family routines. Precariousness is often expressed in the flawed social networks, with even the removal of family and friends.

Other repercussions of the ZVCS on the subjective maternal position identified by us are also pointed out in other studies on malformation and motherhood<sup>23,30</sup> and move towards anxiety, depressive processes, in which there are great difficulties to carry out the work of mourning.

In our research, we followed the story of a baby whose mother and grandmother participated in the groups. The mother produced an emotional withdrawal vis-à-vis her baby, who underwent surgery and several hospitalizations. She struggled to look at and touch him. Care was transferred to the grandmother. We can understand that the child's future uncertainty may have hindered the maternal subjective investment, acting as a brake on the circulation of affection and mother-baby care<sup>23</sup>. Thus, the "primary relationship"<sup>31</sup> (p. 165), a motherhood-specific theme, deals with establishing the affective bond with the baby, of the mother recognizing the baby as her own and giving in to his/her needs is, sometimes, conflicting<sup>23</sup>. It is important to emphasize, in this case, that the maternal affective withdrawal and the difficulties of exercising the caregiving function occurred in a context of significant social vulnerability. The support network's fragility was evident: the father's abandonment, the unconsolidated marital relationship, and the mother with no job placement and living only on the continuous cash benefit to which the baby was entitled by social security.

### Care: maternal role, overload, and adaptation

Pregnant women and mothers were the central figures in the Zika epidemic due to their anguish and afflictions and their observation skills. From their reports, we could build scientific knowledge about the babies' neurological changes<sup>21</sup> from their accounts.

Maternal role showed several faces in our study: expression of resistance and struggle, whether for health care and social rights; confrontation with doctors; and a face of mothering in the context of illness.





The demands of a baby born with special health conditions require a maternal functioning proper to the context of biomedical care, traversed, in the case of the Zika Virus epidemic, by a lack of knowledge about the disease and its developments, which becomes part of the experience of households:

I look at everything on the website. I'm always looking to read so that I can understand a little more about the disease. [...] Because I will question it if I think it is wrong. (Jaspe, mother)

Doctors have their written theories, but the child here live is another thing. You have to listen to what they have to say, yes. Of course, they studied and know more than us. However, they have to listen to our opinion as mothers. So, you have to speak. I ask everything. (Safira, mother)

In some cases, mothers showed an active presence and influence in decisions regarding the therapeutic plan, operating complex collaborative relationships:

The doctor told me that my daughter would not last that long and that they had already tried all the medications. [...] This argument made me think about cannabidiol again. [...] The doctor I trust most came, and I said [...] "You tested my daughter with eight drugs, and I accepted. You switched to a suppository, I accepted. I accepted to test the VPD [short for Ventriculoperitoneal Derivation, used for treating hydrocephalus], and I am asking to accept testing a natural therapy". She said there were no studies on this disease, but I questioned that there were no studies on the treatment of Zika and were testing it on our children. She said she authorized me and gave me the paperwork for me to try [judicial authorization]. (Jaspe, mother)

In caring for babies with ZVCS, and as is usual in chronic child conditions, mothers become full-time caregivers, governed by hours of care, tests, procedures, and medications<sup>5</sup>, hindering glimpsing their life projects:

He [the baby] takes all her time. (Peridoto, father)

Leadership, exhaustion, and suffering also marked the lives of mothers:

There are days when we can't take it. We try to be strong most of the time. However, there are times when you need to vent and cry over and over again. [...] And sometimes people think that you are crying so that people feel sorry. Moreover, it's not. You don't even want to talk. You just want to cry so you can take that weight off. (Jaspe, mother)



The maternal burden in the sick baby's daily care is another factor of suffering, hindering the temporary leave for rest or even care for other children. This maternal experience of extreme child dependence, which involves her life continuously and intensely, marks the reports about the Zika epidemic<sup>2,32</sup>. In this study, some mothers narrated with great suffering the distance, especially emotional withdrawal with their other children. In some cases, care for other children has been transferred to grandparents.

Guilt also emerged in the narratives, expressing the difficulties experienced by mothers in this specific context of treatment:

I was unable to interact with the stimulation. Then I started to cry. I felt very guilty. (Rubi, mother)

It's like an evaluation every time I come here or go to physiotherapy or speech therapy. An evaluation of me, not she [...] She lost much weight. However, I know it was not my fault. We are feeling much guilt. [...]. Because I fought for it, so that she gains weight, but to no avail. (Calcita, mother)

We can understand that this feeling of guilt expresses an ethical sense of compassion and reparation proper to responsibility regarding the other<sup>33,34</sup>. The baby's developmental difficulties trigger intense fears of failure<sup>31</sup>. They seek to adapt to the care situation and develop a "know-how" to address their different and frail children<sup>35</sup>.

The "life-growth"<sup>31</sup> theme (p. 164) underpins one of the motherhood-specific thematic axes, which refers to the intense fear about babies' life and development. Throughout the study, this theme became central with the growth of babies, who completed their second year of life at the end of the research. Due to the neurological changes, the intense fear translates into concern with the development stages' markers.

Thus, the difficulties of anticipating development become a source of distress. Anticipation is proper to the experience of temporality and is protective. It is a guiding thread for symbolization processes<sup>36</sup> and, in the case of children, for understanding the variations in their development.

Williamson's study<sup>5</sup> with narratives of mothers of children with ZVCS points out that time is experienced simultaneously as uncertainty and hope. He notes that "caregivers also live between eternal waiting and crises, between hope and its lack thereof. [...] While present, hope is on hold, waiting for the future to unfold"<sup>5</sup> (p. 689).

Based on the complex and unknown manifestations of ZVCS, the reports show some parents' responses in the face of the unpredictable future. Such responses are



permeated by the paradox of wanting to turn only to the present, “thinking about today”<sup>35</sup>, but at the same time, imagining the possibility of overcoming the limits of development that frighten these parents:

I hope to see him walking. I met a girl with microcephaly, which filled me with hope. Because if she walks and talks, my son can also walk and talk. It helps me with treatments. So, I live day by day, with much hope that he will walk, talk, play ball, and do everything. (Tanzanite, mother)

The hope of overcoming was present in the account in which children with microcephaly manage to develop closer to the desired condition:

There is a 10-year-old boy with microcephaly where I take him for physiotherapy. He was there, running, playing ball. His mother said that he was very strict and was running and playing ball. (Espinela, mother)

The imaginary way of building a positive representation for the future seeks to allow withstanding the suffering of confrontation with the limits imposed by illness<sup>37</sup> and which are still not clear to parents. A psychic work of adaptation that seeks to establish continuity.

We can identify weaknesses and uncertainties at the care level, but simultaneously, the search for life-integrated care, which is expressed in the possibility of parents to be satisfied with their child to invest in their potential:

[...] you understand that your child has grown, that he needs to have some independence and achieve certain things. [...] Realizing that, despite the disease, she is developing and interacting is very good! So, things that I expected she would do as a baby, I see her doing them now [...] Next year, I will put her in the nursery because I know she will be happier. [...] I imagine that she misses living with other children. (Calcita, mother)

I play with him. I don't put limitations on him. We went to a party one of these days. There was a pool ... he got in the pool! It is not because he is sick that he will not get in. Existing limitations are enough. I treat him like a normal child. (Tanzanite, mother)

In some cases, paths of shared care are pointed out with other family members or daycare centers. The demand for children's socialization and introduction in school life intensifies with growth.

The support network, both family and institutional, is fundamental to favor the care and the emotional balance of the mother, with a “protective continent”<sup>15</sup> function (p. 116). However, lack of support and family and institutional solidarity were also found, expressing psychosocial fragility.



Grandparents are considered fundamental figures and can fulfill a supportive role and curb parents' vulnerability<sup>23</sup>.

So, we carry on ... She is my trusted companion [refers to the mother]. She accompanied me in the exams. When I had the baby, she came with me, stayed with me. She takes care of my daughter so I can work. Because I have to work. (Safira, mother)

Although there is a lot of dependence and many treatment needs, some mothers sought moments when they could be alone, and therefore a little more separated from their children, turning to themselves. At the end of the research, with children almost two years old, the investment in other activities, particularly studying or working, was more present on the part of the mothers:

I went on leave because I worked before. And then I put her in the nursery and went back to work. (Painita, mother)

I go to college: mine is semi-classroom. I need it because it is my safety valve. Some days, I'm at home and cry over and over again. I put on ten kilos of makeup and go to college, and everything goes away [...] I come home ready to face the whole battle again, of crisis, husband, and the oldest daughter. College gives me gas to move on. (Jaspe, mother)

Although our research and several studies on Zika<sup>7</sup> reaffirm parenting models in which the mother is the primary caregiver, and in many cases, the father is absent, it is essential to highlight that we found a more nuanced reality, with some care sharing reports. An exemplary case was narrated by the father himself, who brought his daughter for a visit, without the mother's presence:

I usually bring her. Because her mother works in the morning [...] I stay in the day, and her mother stays at night [...] I spend time with her ... rest ... I help her. She has her time. She does her things. I do mine ... When she is home, I go to football. We go out. [...] We are living as normal as possible. (Heliodoro, father)

It is important to note that the possibilities of having the support of a daycare center to share care also depend on the severity of the children's organic changes. Throughout treatments, the parents were faced with unforeseen circumstances and, in the most severe cases, with subsequent hospitalizations. It is a life of stopping and starting over, imposing precariousness<sup>5</sup> and difficulties in sharing the child's care and self-care.

While we observe the desire and even onset of experiences of sharing the child's care with relatives or daycare in part of the maternal narratives, this process reflects the resources affordable to few families, portraying inequality and social vulnerability



processes. Intersectoral public policies are crucial to enhance some level of maternal autonomy, particularly ensuring access to daycare centers, which implies coordinated public education and health policies.

## Final considerations

This work discussed the intense parental impact of the birth of babies with malformations, psychic reorganizations, particularly maternal ones, and consequences on care.

In ZVCS, lack of knowledge about the disease and its effects was markedly experienced at the onset of the epidemic by family members and health professionals, increasing suffering. The maternal role, a hallmark of studies on the Zika Virus, originates in care ethics. It derives from the affective bond with her child, the mother's effort to adjust to her baby, and becomes the source of her hopeful perspective and basis for struggles for health care and social rights<sup>33,34</sup>.

The complex and unknown manifestations of ZVCS, the baby's developmental difficulties, and the unpredictable future lead parents to adapt care and develop a unique way of dealing with their different children.

The maternal experience of extreme child dependence involves continuously and intensely hinders these mothers' glimpse towards other life horizons. It is necessary to reflect on the excessive accountability of women who usually become responsible for the daily and intense care of children with severe disabilities. It is essential to highlight the sociopolitical context's role as symbolic support, the capacity for continence for parents, and social inclusion, primarily through public policies in health, education, social assistance, and the law. The need for actions that articulate health and education and support the children's school inclusion is highlighted.

We conclude by pointing out that this paper portrays only part of the research. Among its limits is the lack of a socioeconomic profile of relatives. We understand that it would have been essential to continue the research to portray children and their families' current situation.



## Authors' contribution

All authors actively participated in all stages of preparing the manuscript.

## Funding

This paper presents part of the results of the research “Psychosocial Implications of the Zika Virus Congenital Syndrome (ZVCS): the experience of family members in the care of children with neurological disorders from a group device” financed by the Research Incentive Program of the Fernandes Figueira National Institute of Women, Children and Adolescent Health (IFF/FIOCRUZ).

## Acknowledgments

We are grateful to family members who were willing to participate in the study and the Research Incentive Program of the Fernandes Figueira National Institute of Women, Children and Adolescent Health - IFF/FIOCRUZ.

## Conflict of interest

The authors have no conflict of interest to declare.

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### Editor

Rosamaria Giatti Carneiro

### Associated editor

Joana Raquel Santos de Almeida

### Translator

Jean Pierre Barakat

### Submitted on

12/18/19

### Approved on

11/16/20



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O artigo trata de experiências de familiares no cuidado de crianças com Síndrome Congênita do Zika Vírus (SCZV) e objetiva analisar o impacto do nascimento do bebê com malformação, as reorganizações psíquicas parentais e seus desdobramentos no cuidado, particularmente o materno. Foi adotada abordagem psicossocial, de base psicanalítica, em diálogo com estudos do campo da Saúde Coletiva. São analisadas narrativas de familiares de 32 encontros grupais realizados em ambulatório de um Instituto de Pesquisa no Rio de Janeiro, Brasil, em 2017. O processo de análise pautou-se na psicossociologia e na análise temática. Angústias, incertezas e sobrecarga marcaram a experiência parental. As dificuldades de desenvolvimento do bebê levaram os pais a um modo singular de lidar com seus filhos e à construção de caminhos de esperança e resistência. O protagonismo materno tornou-se a base para lutas nas áreas social, de saúde e educação.

**Palavras-chave:** Zika vírus. Deficiência. Cuidado. Maternidade. Família.

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El artículo trata sobre experiencias familiares en el cuidado de niños con Síndrome Congénito del Zika Virus y su objetivo es analizar el impacto del nacimiento del bebé con malformación, las reorganizaciones psíquicas parentales y sus desdoblamiento en el cuidado, particularmente el materno. Se adoptó el abordaje psicossocial, de base psicoanalítica, en diálogo con estudios del campo de la Salud Colectiva. Se analizaron narrativas de familiares de 32 encuentros grupales realizados en ambulatorio del Instituto de Investigación en Río de Janeiro, Brasil, en 2017. El proceso de análisis se pautó en la psicossociología y el análisis temático. Angustias, incertidumbres y sobrecarga señalaron la experiencia parental. Las dificultades de desarrollo del bebé llevaron a los padres a un modo singular de lidiar con sus hijos y a la construcción de caminos de esperanza y resistencia. El protagonismo materno se convirtió en la base para luchas en las áreas social, de salud y de educación.

**Palabras clave:** Zika virus. Discapacidad. Cuidado. Maternidad. Familia.