

eISSN 1807-5762

# **Articles**

# "The fight is ours": the experience of caregivers of children with congenital zika syndrome

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"La lucha es nuestra": vivencia de cuidadoras de niños con síndrome congénito del zika (resumen: p. 16)

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The study analyzed the experience of caregivers of children with congenital zika syndrome, both in family and social context. It is a qualitative study with ten caregivers of children with congenital zika virus syndrome, in a Pernambuco referral service for children with disabilities, from November 2018 to March 2019. Data were collected through semistructured interviews and interpreted by thematic analysis. Caregivers, especially mothers, dedicate themselves entirely to their syndromic children's care, facing daily struggles in search of better living conditions, abandoning dreams, jobs, studies and facing financial difficulties as well as for the care of other children. Thus, health actions focused on the uniqueness of families are necessary to enable the offer and / or strengthening of support networks as well as to expand the possibilities for better living conditions for both women and their children with the syndrome.

Keywords: Child health. Zika Virus. Developmental disabilities. Women. Caregivers.



# Introduction

The Zika epidemic, which affected mainly the Brazilian Northeast, affected some pregnant women and caused the zika virus congenital syndrome (ZCS). The most affected were young, single, with low education, living in more marginalized and disadvantaged areas of the cities. Such situation has been impacting the emotional, financial and daily life of these women<sup>1,2</sup>. Thus, "the epidemic has not been equitable, as it has preferentially affected women from disadvantaged social strata", "characterizing it as a "disease determined by the social health inequalities present in the country"<sup>3-5</sup>.

In the period from October 2015 to January 2019, 3,332 cases of alterations in growth and development were confirmed, possibly related to Zika virus infection and other infectious etiologies. The Brazilian Northeast region stands out with the highest number, where, through clinical-radiological or clinical-laboratory criteria, 2,122 cases were identified<sup>4</sup>.

The pathophysiological changes caused by ZCS in children, such as cognitive, sensory and motor deficiencies, are common to other congenital diseases, but with the aggravating factor of rare signs, such as microcephaly, severe abnormality in neurological development; eye and hearing abnormalities; multiple contractures; altered muscle tone; seizures; swallowing problems; and brain abnormality (intracranial calcifications; brain atrophy; abnormal cortical formation). However, some do not present microcephaly at birth, but only in the postnatal period. Although the severity of the situation is evident, with negative repercussions on growth and child development, the consequences of ZCS and the future of these children are still unknown<sup>5,6</sup>.

The repercussions of ZCS go beyond a discussion of physiopathological nature, leading to reflections about the political, economic, and social role of the State in studies in the area of anthropology, law, and history. Silva *et al.*<sup>7</sup> emphasize this problem from the point of view that high investments are directed to research and technologies aimed at the extinction of the *Aedes aegypti* mosquito, while the care and support for the people involved are weakened. Furthermore, the families of these children have constitutional rights that, in turn, are not guided on how to use them<sup>7</sup>.

Uncertainty by science and invisibility by the government cause even more emotional stress in the family that takes care of the child with special health needs (CRIANES), CSHN which seeks in several rehabilitation services the answer to the health care demands, indispensable to the biopsychosocial well-being of these children<sup>8</sup>.

The birth of a child with ZCS is a challenge within the family; several factors, such as the higher demand for care, the intense routine in health services, social prejudice, higher financial expenditure to meet the child's health needs, and also, the abandonment of other caregivers' social roles, in order to be exclusively available to meet the needs of the child<sup>1,9</sup>, completely change the family's daily life.

Therefore, it is notorious that these parental nuclei suffer with physical, financial, and psychological overloads. Evidence indicates that the caregivers of children with ZCS with developmental delay experience emotional stress<sup>2</sup>, and more, have higher scores of depression, reporting that the biggest challenges are economic and child



care<sup>10</sup>. Thus, the suffering arising from difficulties in various socioeconomic spheres faced by the caregivers of children prevails, which can affect the family's mental and physical health<sup>10</sup>. Moreover, these caregivers are more prone to the onset of physical diseases and comorbidities<sup>11</sup>.

In view of the above, we seek to evidence how the family daily life of caregivers of children affected by ZCS is being affected and the challenges they face. Therefore, the question is: What is the experience of caregivers of children with ZCS in the family and social context? To answer this question, the present study aims to analyze the experience of caregivers of children with zika congenital syndrome in the family and social context.

### Method

This is a descriptive-exploratory, qualitative study, and a final paper of the Professional Master's Degree in Family Health, carried out in a neuropsychomotor rehabilitation service for children and adolescents with special health needs in a city in the metropolitan region of Recife-PE, Brazil, where children with ZCS are assisted.

The participants of this research were selected by convenience, among persons who were in the service for care, composing the sample ten caregivers of children with congenital syndrome by zika virus, who met the following inclusion criteria: being the main caregiver of the child with the mentioned syndrome, being over 18 years old, being registered in a specialized reference service of the city and living in the city where the research was carried out. The caregivers who did not attend the reference service for the child's follow-up for three consecutive appointments were excluded.

The empirical data were collected between November 2018 and March 2019, in the rehabilitation service itself through an in-depth semi-structured interview, recorded and transcribed in full conducted by the main researcher herself for later analysis.

A semi-structured script was used with the following guiding question: "What is your experience, in society and family, with ZCS?". The end of the collection followed the sufficiency criterion, when it was possible to understand the multiple dimensions of the object of study, from the data collected<sup>12</sup>, there was a dialog between the researchers to determine saturation.

The empirical material was transcribed in full and submitted to thematic content analysis<sup>13</sup> with organization of the material and first classification; successive readings to trace the horizontal map and apprehension of the structures of relevance; and, transversal reading, regrouping in two nuclei of meaning to reach the objective of the study, which were: "Protagonism and women's struggle to care for the child with ZCS; Impacts of ZCS on caregivers' lives".

The caregivers were personally introduced to the research and the responsible researcher in a first moment and those who agreed to participate signed the Free and Informed Consent Form, according to the guidelines and regulatory norms for research involving human beings, established in Resolution no. 466/12 of the National Health Council. The research was approved by the ethics committee.



The participants were identified with the letter "E" for "Interview", followed by the numbering corresponding to the chronological order in which the interviews were conducted: "E1", [...], ensuring their anonymity and confidentiality of information.

In order to ensure rigor in the study, the Consolidated Criteria for Reporting Qualitative Research (COREQ) was used as an auxiliary tool.

The empirical data were analyzed according to the perspective of the Ethics of Alterity, developed by Emmanuel Levinas, which is based on the relationship of the Self with the Other in a plural relationship, starting with respect for the other and following with a moral consciousness of the Self that puts itself at the service of the Other<sup>14</sup>.

Moreover, the Ethics of Alterity<sup>15</sup>, advocates the opening of the "I" to the "Other", in particular, the Other who is different, who should not be excluded, set apart, discriminated against, but welcomed, accepted in his differences and singularities.

Alterity, as otherness, is not only an alter ego. Is what I am not: is weak while I am strong; is the poor; is the widow and the orphan [...] or else is the foreigner, the enemy, the powerful. [...] the intersubjective space is initially asymmetrical<sup>15</sup>. (p.113)

It is in the opening to the Other, seeing his/her different side, which must be respected, that Alterity is concretized.

#### Results

The study participants were nine mothers and one grandmother, one caregiver was under 20, seven were over 20 and under 30, and two were over 30. Seven women declared themselves black or brown and three white. Six caregivers had incomplete elementary school education, three had complete high school education, and one had complete college education. Regarding the number of children, three mothers had only one child with ZCS, six had two children, the grandmother had two adult children and took care of her grandchild. Four women had family income lower than the minimum wage, five reported incomes between one minimum wage and less than two, and only one had a higher income. As for marital status, eight mothers were living in a stable union, one mother and one grandmother were single. The children (children/grandchildren) were between 19 and 36 months old and participated in motor, visual, auditory, language, and cognitive and behavioral skills therapies, of these, six attended more than one rehabilitation service.



# Protagonism and women's struggle to care for the child with congenital syndrome of the zika virus

Women are the main caregivers of children with ZCS, especially mothers. They assume the integral care, experience emotional stress for being inserted in a routine of intense treatment with their children and for depending on the public power for the displacement to the child's therapies.

Thus, when reporting their experience with the child, they refer to their daily life as a "battle" or "struggle", permeated by the fatigue related to the daily care of these children and the visits to rehabilitation services and to specialists:

It is a battle with her, some days I am tired because we have to wake up early to go to the doctor, but this is normal, I am already used to it [...]. When I go to the doctor's I get very tired, some days I leave at 4:40 and arrive home at three in the afternoon. Depends on the car from the city hall, where it picks me up [...]. (E6)

We go to other places, we don't just come here, the A service even, we go and spend the whole day there, we go in the Town Hall car, there is traffic, it takes time because it will leave all the mothers at home, then when I get home, sometimes it is eight o'clock at night, I leave at ten in the morning and arrive at eight at night, the person already arrives dead, tired [. ...] Yes, the fight is only ours [...] The biggest difficulty (for child care) is the bath time, because they are heavy, and he still has the GTT (gastrostomy tube), if you let him, he pulls it out. (E1)

By assuming the role of mother, protector and responsible for the child with ZCS, these women assume such activities as their main role in society, facing the situation as "normal", because this becomes the daily routine of their lives, thus, the family reorganizes itself within its context and possibilities, for a better condition of life and health for the child.

Even though the child has other associated diseases, which causes frequent visits to rehabilitation services and increased work with the care at home, these women consider this situation as a common practice, although a contradiction is found in some statements:

[...] now she has therapy, right? Because before, as she has heart disease, the doctor had not allowed her to do therapy because she got too tired when she started doing it, so she couldn't [...] For me it didn't change anything, her care changed, but for me she is a normal girl just like the other [the other daughter]. (E3)

It has been normal; he is like normal. [...] his thing is that he only wants to stay on my arms, it is bad to see him fed, because he only wants to eat lying down. (E7)



With her it has been very normal. I take care of her well. When she is awake, I give her all the attention [...] When I am at home, I only pay attention to her, play with her, sit with her, give her a bath and then put her to sleep, then when she sleeps, I clean the house a little bit, what I can't clean I leave to do at night. [...] Many things changed, before I only had one and today, I only live in a doctor, doctor, doctor, different, normal to take care of her. (E6)

Then his routine, there is this problem of taking him to therapy, there was a time that he did it every day [...] It is very hard. (E10)

There was a case in which the child was abandoned by the mother, so the grandmother took over the care since birth. Since then, this woman took upon herself the commitment of full-time caregiver who, despite the difficulties, does care with love and dedication, still recognizing such function as divine designation, as reported below:

There are many mothers who separated because their child had microcephaly, but there is also a case that the woman let the father stay with the child. He (grandson) himself was despised by his mother, as soon as he was born his mother despised him. I just didn't bring him into the world, but I was the one who did everything. As soon as he was born, she (mother) turned her back. Her family, nobody wanted to know about him, everything was me, I was the mother, the father, everything. [...] When the doctor gave me the news that he had microcephaly, I said: for me this is normal, this is nothing, for me he is a perfect child, normal [...], but I committed myself, I will do everything. God gave it to me, he is mine [...]. (E1)

### Impacts of zika congenital syndrome on caregivers' lives

The arrival of a CSHN changes all family dynamics. The caregivers start to adapt to the challenges imposed by the new situation, even if it is necessary to give up personal life projects, such as work and study.

The caregivers' reports show the impact of these changes, when becoming the main caregiver of a child with ZCS:

Before having him, I could work and leave whenever I wanted, after him, I already had to change my shifts that are all at night, that my husband can stay with him. (E10)

It is a big difference, because before I studied, he [father of the child] also studied, we dated, it has been three years that I don't study, with him [son] I don't have a head anymore. (E7)



Everything changed, everything, everything! I stopped my course, I used to do a Nursing course, work, I am no longer working, everything changed, my life totally changed, my sleep routine, everything. (E8)

I had to leave my job, because I was always with him at the doctor's and doing the exams, consultations, I kept taking certificates. I already had seven years in this job, then when they fired other people, they fired me. His father was fired a month after I left. (E9)

The needs of children with ZCS, which are several, go through therapies in different rehabilitation services, food, medication, and instruments for stimulation, which result in greater expenses for the families. Considering that many caregivers lost their jobs and some children still don't receive the Continuous Cash Benefit of Assistance (BPC), this reflects in financial difficulties for the family and, even receiving the BPC and having access to the Brazilian National Health System (SUS) services, such value does not supply all the children's needs, according to the caregivers' statements:

I don't receive help, everything is bought, medicine, everything, there is nothing given, her medicines are very expensive. I have already run so hard after the help (benefit) and the medicines, but I couldn't get it. It is a lot of expenses [...]. (E4)

But it is a lot of spending, her milk only comes five, then the nutritionist asked me a paper to ask for fifteen, then we have to buy, I buy diapers, what I get is a basic food basket from the F service and from the city hall too, there are also the medicines [...] But imagine one person working alone (the husband). Because I can't work anymore, before I worked, now with her how can I? Who will I leave her with? (E6)

If I depend on this government money, I bought a feeding chair for him, I still buy milk, because what the government gives is not enough. I went last month and it still hasn't arrived, if you are going to wait for the government, you'd better buy it. It's been two months since his milk arrived, which he needs, right? I have to buy it. (E7)

It was also possible to identify that caring for the child with ZCS is a priority in the lives of the study participants. This exclusive dedication to the child results in these women abstaining from leisure time and from self-care:

Everything has changed, in everything you have to prioritize him, everything is more him. You have to pay more attention to him, even to fix my hair, to fix me, he cries, he doesn't want to be with anyone, it's agony. (E9)



After she arrived everything changed. In the old days I was more liberal to go out and do my things, nowadays not, today the free time is for her, you want to do something, want to go out and you can't because of her (E4).

When he is sick, I don't do anything, I don't take care of the house, I don't take care of myself [...] Today we don't go out anymore, and when we go out, we come and go because of him [son]. (E7)

Giving up the care of other children and delegating it to relatives and friends is also a consequence of the impact of the syndrome in the lives of these caregivers:

[...] I had to leave my other daughter in the hands of one and another, sometimes with my cousin, with my mother, with a neighbor, and I am worrying about both. Just now to come here [service B], I left the other with the grandmother [...]. (E3)

I have another son of seven years, when I go out with her, he stays with my mother [...]. (E8)

I still have my other (daughter) to take care of. The other stays more at my grandmother's house, because it is all day with him, the father works, I am all day with him in my arms. (E7)

# **Discussion**

The experience of the caregivers of children with ZCS is permeated by challenges faced in the social context in which they are inserted, evidenced by the need for change in lifestyle, with the absence of essential resources and, especially, the need for a wider network of social support, considering that everything is concentrated on family support. This syndrome imposes substantial and complex difficulties as a result of the children's greater dependence on care, causing impacting changes in the family's routine and life, especially that of women.

Regarding full-time child care, the results of this study are consistent with the literature, which shows that women give up their jobs and other personal activities to care for their children with special needs. This situation is imposed by society, so that the mother assumes this function exclusively and, to do so, gives up her social, personal, and professional life, having to divide herself into caring for other children, husband, and household chores<sup>2,16,17</sup>.

Although the care of the child with ZCS is performed almost exclusively by the mother, one report highlights that the father shares the responsibility of care with the mother, which allows the mother to work.



The literature shows that fathers can also have active engagement and involvement in the care of the child with special needs, and when they do, they are skilled and willing to provide the best care for the child. However, these actions by the fathers are still performed in an auxiliary manner, with no male protagonism<sup>18,19</sup>.

The caregivers' exhausting routine, involving constant visits to appointments, exams, and therapies, prevents them from conciliating work and/or studies with the care of the child with ZCS, making these women leave even their social life in second place<sup>9</sup>. This fact is further aggravated by the fact that these women are single and poor, in most cases, in which unemployment further restricts the family's financial conditions<sup>16</sup>, and may have a negative impact on their quality of life.

In the ethics of alterity proposed by Levinas, there is an emptying of the "I" in favor of the Other; in this connection between them, the "I" becomes responsible in such a way that even if there are negative costs to him, his life only makes sense if in favor when he is occupied in the search for the well-being and justice of the Other<sup>20</sup>. Such philosophical concepts provide the basis to ground the experience of the caregivers of children with ZCS, who demonstrate exactly this articulation and commitment of the Self (caregivers) with the Other (children with ZCS)

The combination of caring for the child with ZCS and the demands arising from his clinical condition contribute for this mother/caregiver to feel restricted or isolated from the social contacts previously established, because there is no more time for personal interests and leisure activities<sup>10,21</sup>. In these situations, the woman neglects her self-care, does not recognize herself as being separate from her child, and a relationship of mutual dependence occurs inside the mother/child binomial<sup>22</sup>.

Professionals should pay attention to the women's commitment to the care of children with ZCS, since these caregivers are more likely to develop depression and anxiety, due to the high load resulting from daily activities, added to the emotional projection linked to the child since pregnancy and weakened by the discovery of the diagnosis<sup>23</sup>. Thus, this overload results in negative impacts on the emotional well-being and quality of life of these women, and can lead to lack of care for other family members. However, this reality can be changed if there is effective support to these families<sup>10,24</sup>.

In this direction, it should be noted that Levinas proposed not a restricted bond of the I with the Other, but a relationship that is also open and plural, which should and can encompass several actors, considering that there are several human beings, thus proposing the Alterity ethics<sup>25</sup>. Thus, it is possible to denote that although the caregivers have the protagonism in the care of children with ZCS, this imposed overload that brings negative effects to the women could be attenuated with the more active participation and accountability of other caregivers.

Contrary to what is socially established as to the full dedication of the mother, in the study in question there was a situation of abandonment of the child by a mother, leaving the grandmother with the responsibility for the child's care. The rejection evidenced was also found in another study, in which the feelings of denial of the disability, sadness, prejudice, fear of the different and of the difficulty are intertwined in the families and in the caregiver, which sometimes culminates in the abandonment of the child<sup>26</sup>.



Caring for a child with ZCS demands radical changes in the whole family routine <sup>16</sup>. This reality was also evidenced in the present research, corroborating the study that sought to understand how family members of children with microcephaly by Zika virus reacted emotionally to the diagnosis and the impact of this event on family dynamics. The findings show that families had to make many adaptations in their daily lives to care for the new family member. The caregivers, in this case, the mothers, assumed the continuous responsibilities with the support of their partners<sup>2</sup>.

Therefore, it is necessary to offer these women moments of relaxation and assistance to their health, as well as to provide intervals for resting and support from other family members, thus softening the caregivers' overload<sup>27</sup>.

Therefore, it is necessary that the professionals know the singularity of the daily life of these families and their needs, in order to offer a qualified care, to help them in whatever is possible in the family organization as a whole. For this, the relationship developed between the professional and the family must be based on dialogue and sensitive listening<sup>28</sup>.

Regarding the future of these children, the women caregivers give new meaning to their lives based on the reality they live in, they experience the hope of a future, even if unknown, and this feeling makes them fight for their children<sup>29</sup>. A study<sup>30</sup> shows that this endless pilgrimage in search of solutions in an attempt to give more quality of life to the child affected by ZCS, marks the experience of maternity as a sacrifice on behalf of the other, making the figure of the caregiver valued by society and by them.

About this, life in the function of caring for a CSHN is sometimes referred to as a daily struggle in the search for the guarantee of rehabilitation therapies. In view of the visibility in the media, the caregivers of these children seek to rely on their rights, trying to understand the problems they experience. They seem to be relentless in the face of the daily care itinerary, despite the suffering caused by the routine struggle. Thus, the families seek support and knowledge to fight for the child's rights in such a way that these forces transcend the financial benefit and go through judicial, educational, and health care aspects<sup>31,32</sup>.

It is important to highlight that the precarious financial situation of these families is emphasized in the experience of these caregivers, for even when they perform treatments in SUS services, receiving the BPC, one must consider that the costs with the treatments and care of the CSHN, frequently exceed the value of the benefit. Moreover, with the woman leaving work, this situation becomes even more difficult<sup>1,10</sup>.

Thus, to have access to special food, medicines, orthoses, and rehabilitation devices, these families fight an endless battle with the State, because many times they do not get support, or the quantity is minimal for the determined period, having to ask for financial support from relatives and friends to take care of the child. Reinforcing this aspect, a study<sup>33</sup> points out that due to the bureaucratization of the assistance and the specific needs of these children, the mothers seek help from Non-Governmental Organizations (NGOs) for guidance about their rights. These institutions, besides giving support, act as mediators for the access to health, welfare, and transportation services.



In our daily practice with the caregivers of children with ZCS, we notice that they often feel helpless and neglected by the State. However, they seek strength to conquer their rights and experience the routine of caring for their children, outlining a profile of the warrior woman. As shown by a study<sup>33</sup>, expressions such as "struggle" and "battle" reveal opposition to the idea of mourning, sadness, and abandonment, demonstrating these women's power of resilience.

Research conducted with parents of children with ZCS showed impacts on their mental health when faced with the challenges of caring for these children. Compared to fathers, mothers experienced more negative effects, lower levels of life satisfaction, higher levels of fatigue and psychological distress, and consequently, lower levels of mental health<sup>34</sup>. This is because mothers are more involved in the care of their children.

Thus, the emotional support is essential to reduce the caregivers' overload, a fact evidenced by another study carried out with 191 mothers of children with disabilities, which revealed that the greater amount of social support was related to higher levels of happiness, as well as a reduction in stress, anxiety, and feelings of guilt<sup>35</sup>.

Therefore, these caregivers often find themselves as a frail individual who, despite this situation, remains an otherness. Thus, to care for the other conceiving him or her as an alterity, a singular person, is to realize the infinite responsibility in regard to him or her.

For these reasons it is necessary to support families of children with zika virus syndrome, in order to empower them for the demands imposed by the child's condition, helping in ways to face difficulties, even if the external support is weakened<sup>30,36</sup>. Thus, it can be seen that the child's and the family's well-being go together, and that their adaptation depends on the support network and the services made available<sup>36</sup>.

#### Conclusion

The understanding of the experience of caregivers of children with zika congenital syndrome in the family and social context, enables us to reflect on the figure of the women in this process, as a synonym of struggle and constant battle for rights and better living conditions for their children/grandchildren. The family daily life changes in face of the needs of the CSHN, involving therapies, medicines and necessary supplies for rehabilitation, which, associated with the obligations neglected by the State, impacts the life of these women in a negative way.

Despite the existence of public policies, the media repercussion and referral services created to meet the demands of these children, the gaps in care impose challenges to the family members who face the lack of social, legal and health support. In this context, the woman/primary caregiver dedicates herself exclusively to the care of the child with ZCS, giving up her personal, professional, and family life, feeling overburdened and lonely in this process.



As limitations of the study, we consider the fact that the participants were only the main caregivers of children with ZCS, not allowing a greater representativeness of other family members, in order to understand family relationships.

For these reasons, it is suggested to develop studies that contemplate the family sphere of the child with ZCS, in order to know the challenges faced by all family members, as well as the influence of the family context on the care of this child, considering that the major focus of studies falls on the main caregiver. It is also suggested that the professionals of the family health team be trained and supported by the Núcleo de Apoio à Saúde da Família (Family Health Support Center), so that they can contribute to the care of the child with ZCS and his family, thus offering a comprehensive care to this group.

#### Authors' contribution

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

#### Conflict of interest

The authors have no conflict of interest to declare.

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**Editor** 

Miriam Celí Pimentel Porto Foresti

Associated editor

Fernando José Guedes da Silva Júnior

Translator

Félix Héctor Rigoli Caceres

Submitted on

07/14/21

Approved on

09/16/22



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Objetivou-se analisar a vivência de cuidadores de crianças com a síndrome congênita do Zika, no contexto familiar e social. Trata-se de um estudo qualitativo com dez cuidadoras de crianças com síndrome congênita do Zika vírus, em um serviço pernambucano de referência à criança com deficiência, realizado no período de novembro de 2018 a março de 2019. Os dados foram coletados por meio de entrevista semiestruturada e interpretados pela análise temática. As cuidadoras, principalmente mães, dedicam-se integralmente aos cuidados do filho com a síndrome; enfrentam lutas diárias em busca de melhores condições de vida; abdicam de sonhos, emprego e estudos; e enfrentam dificuldades financeiras e no cuidado a outros filhos. Assim, são necessárias ações de saúde focadas na singularidade das famílias para viabilizar a oferta e/ou fortalecimento de redes de apoio e ampliar as possibilidades para melhores condições de vida das mulheres e de seus filhos com a síndrome.

Palavras-chave: Saúde da criança. *Zika* vírus. Deficiências do desenvolvimento. Mulheres. Cuidadores.

El objetivo fue analizar la vivencia de cuidadores de niños con síndrome congénito del Zika en el contexto familiar y social. Estudio cualitativo con diez cuidadores de niños con síndrome congénito del virus del Zika en un servicio del Estado de Pernambuco de referencia para los niños con deficiencia, desde noviembre de 2018 a marzo de 2019. Los datos fueron colectados por medio de entrevista semiestructurada e interpretados por análisis temático. Las cuidadoras, principalmente madres, se dedican integralmente a los cuidados del hijo con el síndrome, enfrentan luchas diarias buscando mejores condiciones de vida, abdican de sueños, empleo, estudios y enfrentan dificultades financieras y con el cuidado a otros hijos. Por lo tanto, son necesarias acciones de salud enfocadas en la singularidad de las familias para hacer viable la oferta y/o el fortalecimiento de redes de apoyo y ampliar las posibilidades para mejores condiciones de vida de las mujeres y de sus hijos con el síndrome.

Palabras clave: Salud del niño. Virus del zika. Deficiencias del desarrollo. Mujeres. Cuidadores.