

On gestating and giving birth to a child with congenital zika virus syndrome: a case study

Sobre gestar e parir uma criança com a Síndrome Congênita do Zika Vírus: um estudo de caso¹

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Abstract

This study analyzes the context of pregnancy, prenatal care and birth of children with Congenital Zika Syndrome (CZS). A single case exploratory study was conducted with a mother of a child diagnosed with CZS in Pernambuco, Brazil. Data were collected by an in-depth interview and content was categorized into four themes: discovery of pregnancy; conditions of prenatal and childbirth care; conditions of diagnosis and childcare; and feelings involved in the pregnancy discovery and syndrome diagnosis. This case study highlights failures in reproductive planning and in prenatal and childbirth care; unpreparedness of health professionals; and significant changes in the family's routine, which imply difficult choices under a deficient public health care. CZS epidemic uncovered problems that go beyond mosquito vector control. The current scenario highlights the vulnerabilities of these families, intensified by the emergence and consequences of COVID-19, which has further exposed the weaknesses of women's comprehensive health care and the need to maintain an articulated and resolute network in health care and surveillance.

Keywords: Women's Health; Pregnancy; Zika Virus Infection.

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Resumo

Este artigo busca analisar o contexto de gestação, pré-natal e parto de uma criança com Síndrome Congênita do Zika (CZS). É um estudo exploratório qualitativo, tipo estudo de caso único, delineado a partir de entrevista em profundidade realizada com uma mãe de criança diagnosticada com CZS em Pernambuco. A análise dos dados ocorreu mediante a categorização do conteúdo da entrevista em quatro núcleos temáticos: contexto da descoberta da gestação; condições da assistência ao pré-natal e ao parto; condições de diagnóstico e assistência à criança; e sentimentos envolvidos na descoberta da gestação e do diagnóstico da síndrome. Esse caso sinaliza falhas no planejamento reprodutivo e na assistência ao pré-natal e parto; despreparo dos profissionais de saúde; e mudanças significativas na rotina da família, que implicam escolhas difíceis num contexto de deficitária assistência pública à saúde. A epidemia da CZS revelou problemas que vão além do controle vetorial do mosquito. O panorama atual escancara vulnerabilidades dessas famílias, intensificadas com o surgimento e as consequências da covid-19, o que tem exposto ainda mais as fragilidades da atenção integral à saúde da mulher e a necessidade de manter uma rede articulada e resolutiva na assistência e vigilância em saúde.

Palavras-chave: Saúde da Mulher; Gestação; Infecção por Zika Vírus.

Introduction

Gestating a child is, without a doubt, a moment that can cause joy, insecurities, doubts, and curiosity in women. Among these feelings, the fear or apprehension that something wrong or out of the norm will occur is common in the child's formation process. In 2015 and 2016, when the epidemic of a new congenital disease was identified in Brazil and other countries, later associated with Zika Virus (ZV) infection, these feelings indeed permeated the lives of many women who became pregnant or planned to become pregnant.

In the mentioned period, there was an epidemic scenario of malformations in babies, initially characterized by the presence of microcephaly, soon added to other alterations related to the neuropsychomotor development of the child, such as arthrogryposis, brain calcifications, and eye and hearing problems, among others. The national and international media extensively reported the Congenital Zika Virus Syndrome (CZS), which is how it was named later (Aguiar; Araujo, 2016; Andrade; Lima, 2019).

Daily, the news broadcasted information about the situation, declared a public health emergency by the Brazilian government and the World Health Organization (WHO), and showed images of affected children. The fear of having a child with a malformation permeated the imagination and reality of many women and became a great fear (Diniz, 2016).

Unlike the usual arbovirus epidemics experienced in Brazil, the Zika epidemic, with its consequent CZS, presented a greater degree of complexity. This is due, among other factors, to the initial lack of knowledge about the disease, its association with serious congenital malformations, the difficulty in controlling the vector, and the speed with which it spreads in a continental country like Brazil (Brasil, 2016).

Carneiro and Fleischer (2018) state that while some mothers were diagnosed with Zika during the gestational period, this disease was not even considered by them or their physicians in other cases. Despite presenting the characteristic symptoms of Zika during pregnancy, the lack of knowledge about the possibility of congenital infection did not

allow an investigation to conclude the diagnosis. Thus, health professionals considered another condition unrelated to gestational risks, such as a milder virus disease or dengue.

It is noteworthy that prenatal care is essential in the prevention and early detection of both maternal and fetal pathologies, monitoring the baby's healthy development, and reducing risks to the pregnant woman. It is a crucial moment for care, emotional support, and provision of information to pregnant women, clarifying doubts surrounding the gestational moment, in addition to guaranteeing a comprehensive offer to the health of women and children (Piccinini et al., 2012).

The lack of welcome and support for these mothers made many seek information about what their children had by other means (the internet, conversations with other women in the same situation, on social networks, in the corridors of institutions) (Diniz, 2016). Such situations, which occur during prenatal care, childbirth, and postpartum, refer to situations of abuse and disrespect that, as mentioned by Carneiro and Fleischer (2018), often occurred with the use of "procedures performed without consent, without prior information to the parturient, with abusive maneuvers, in moments of loneliness and/or tension" (p. 713).

Due to the differentiated and multidisciplinary care these children need, the mothers, the primary caregivers, need to have a dedication beyond the "normal," with an intense routine in search of healthcare services. This results in an overload for these women, who mostly give up their social and personal lives to take care of their children (Alves, 2018).

The living conditions of families affected by CZS, mostly belonging to the poorer strata of the population and in a situation of social vulnerability, revealed the need to observe this epidemic. It should not only consider its causative agent, but also other aspects related to the social determinants of health, such as socioeconomic, environmental, living and housing conditions, education level, and race/color, among other factors (Diniz, 2016). CZS revealed many other aspects of people's lives, including sexual and reproductive health, gender inequalities, and the

socioeconomic conditions of the affected population (Moreira et al., 2018).

This study sought to understand the conditions in which pregnancy, prenatal care, childbirth, and postpartum occurred for a mother of a child with CZS in Pernambuco. Other women in similar situations share this particular context. It is hoped that the results can contribute to better dialogue and welcoming between health professionals and pregnant women, both in unknown situations and in the day-to-day of becoming pregnant and giving birth.

Method

A single case study was conducted based on the speech of a mother of a child with CZS residing in Pernambuco who became pregnant in the first year of the epidemic. The state was the epidemic's epicenter in Brazil and, between 2015 and 2021, totaled 469 confirmed cases (Pernambuco, 2021).

Data collection was carried out in October 2020, about five years after the child's birth, and an in-depth, semi-structured interview characterized the source of information (Moré, 2015). The interview script sought to identify the changes in the mother's life based on her memories of pregnancy and after the child's birth and her perceptions and feelings about her trajectory in healthcare services.

The identification of the study participant occurred from a research and intervention project aimed at mothers of children affected by the disease. The initial contact with the interviewee was made via WhatsApp, scheduling the day and time. Due to the pandemic situation of COVID-19, data collection was carried out on the Google Meet platform to comply with mandatory health measures of social distance and lockdown. The interview was recorded and transcribed *a posteriori*.

Data analysis was performed from exhaustive and systematic readings of the interview and the categorization of data from the previous interview script. Sequentially, other categories were highlighted according to the content evoked in the interaction between interviewer and participant (Minayo, 2013). Finally, they were summarized in four thematic nuclei: the context of

the discovery of pregnancy, conditions of prenatal and childbirth care, diagnostic conditions and child care, and feelings involved in the discovery of pregnancy and diagnosis of CZS.

The Ethics Committee of the Federal University of Pernambuco (UFPE) approved the research under opinion 4,324,894/2020. Fictitious names replaced the participant's name and other mentioned subjects to guarantee anonymity and confidentiality.

Results and Discussions

The results of this article begin with a brief presentation by Maria, who lent her story, as a study participant, to an analysis of gestating and giving birth to a child with Congenital Zika Syndrome. The analysis of the results was subdivided into three topics below.

At the interview, Maria was 32 years old and had lived in the capital of Pernambuco for almost three years. Before, she was a resident of a municipality located in the countryside of the state, with 365,278 inhabitants, where she worked as a seamstress providing services to companies that make up the clothing hub of this region. Her fourth child, José, was the result of an unexpected pregnancy that took place in 2015. Since birth in January 2016, José had difficulty breastfeeding, irritability, and crying that was difficult to control, which triggered the search for explanations that led her to participate in a joint effort to diagnose newborns with alterations. José was diagnosed with CZS late, at three months old. Without specialized healthcare services to properly care for José, Maria had to travel to the capital of Pernambuco four times a week. This situation led her to quit her job and decide, with her husband, to move to another city. She took José and one of her daughters and left her other two children in the care of her grandmother in her hometown.

An unplanned pregnancy: discovering herself pregnant amid an epidemic of microcephaly in newborns

Pregnancy, for some women, is a period of joy, fear, and insecurities. During the period of the epidemic, these feelings were even more

evident. When observing what was happening with several babies born between 2015 and 2016, many women avoided becoming pregnant for fear that their children would be born with CZS (Carneiro; Fleischer, 2018).

Maria claims that José's pregnancy was not planned or wanted. She had no intention of becoming pregnant, had three children, and used contraceptives. Upon "*realizing that something was wrong,*" she sought gynecological care, which diagnosed her with a "*stain in the uterus*" and referred her to a cauterization procedure. Even though she continued to present several symptoms, undergo tests (pharmacy pregnancy test and Beta HCG), and seek medical attention, until almost four months into her pregnancy, no healthcare professional identified that she was pregnant:

After this cauterization, I had bleeding and extreme pain in the lower part of the belly. That's when the doctor asked me to do a vaginal ultrasound. Then when I did, there was a baby already there, formed, he was actually almost four months old, we just couldn't see the sex (Maria).

After receiving confirmation of pregnancy, the physician from the Basic Health Unit (UBS) limited himself to congratulate her on the pregnancy, ignoring the various procedures performed and medications used (antibiotics and others) at the beginning of the gestational period. There was no concern or information about the possible consequences of such procedures. "*I still have the tests, from the cauterization, the beta, I have everything saved, the ointments I used, the medicines I took orally, everything already pregnant*" (Maria).

Despite the knowledge and availability of contraceptive methods in the public and private sectors, the national survey "*Nascer no Brasil*" (Born in Brazil) showed that only 44% of women who become pregnant plan their pregnancy (Viellas et al., 2014). This demonstrates that problems related to reproductive planning in the country may be related to difficulties in accessing information, communication, and access to adequate methods, failures in continuous availability in

the Brazilian National Health System (SUS), and the guidance of healthcare professionals, resulting in serious inefficiency of the sexual and reproductive health policy.

In the case of Maria, discussed here, failures can be identified concerning the care, either in the anamnesis or in attentive and qualified listening, given that the identification of a pregnancy can be made in different ways, such as the aforementioned physical examination mentioned by Viellas et al. (2014). In addition, prenatal care must guarantee the welcoming of the pregnant woman and the adoption of the protocols recommended by the Ministry of Health (Botelho; Caetano, 2018).

The report also showed inadequate guidance on possible drug interactions (Silva; Rocha, 2016). After confirming the pregnancy, Maria was informed that the antibiotic previously prescribed by another professional could have interfered with the effectiveness of the contraceptive. The information arrived at an inopportune time for a woman of reproductive age who could have better evaluated all her possibilities of choice with the healthcare professional.

Family planning in healthcare services still faces several barriers. Theoretically, there is a diversity of methods. However, only oral contraceptives and the use of male condoms are generally disseminated, detaching from the practice of sexual and reproductive health, including difficulty in introducing the partner at times of choice, agreement, and co-responsibility in the proper use of each method (Pierre; Clapis, 2010). This reaffirms deficiencies in the qualification and permanent education of these teams, especially those of the Basic Health Units, responsible for this care for most of the population.

The delay in discovering the pregnancy resulted in late access to prenatal care. Following the news of the epidemic of children with microcephaly (as they were identified at the beginning), the possibility that the disease could also affect her child brought insecurity and uncertainties that made Maria seek care in the private sector,

in addition to the routine care she received at the Family Health Unit in her territory.

Another reason that led Maria to perform prenatal care in the private health network was the intention to perform tubal ligation, as she was going to have her fourth child and did not want to get pregnant again. However, due to financial difficulties, she gave up and returned to the SUS. This search for the private sector results from the barriers to access in the public healthcare service to perform sterilization.

During pregnancy, Maria did not show any symptoms of Zika, and prenatal tests could not previously detect changes in the development of the fetus. To avoid contamination, she followed the guidelines on using repellents, pants, and long-sleeved blouses to avoid contracting the virus.

I thought that by having a private consultation, I would have more confidence in knowing if, later on, José would be born with microcephaly or not. [...] this doctor requested me to have a very expensive ultrasound with a fetal specialist. [...] I had those ultrasounds that are 3D, those that allow you to see the fetus much better, to see if he is perfect; there was one that even counted the finger bones. (Maria)

Despite available technology, many confirmed cases of CZS were not detected during pregnancy. Pimentel (2018) points out the need to improve equipment and ultrasound professionals and the performance of prenatal healthcare teams. The early diagnosis of congenital alterations can allow the monitoring of fetal development, identify necessary and possible interventions, and better prepare the family for the challenges they will have to face.

The decision to seek prenatal care outside the public healthcare service may also reflect disbelief and/or lack of knowledge about the working dynamics and possibilities of the SUS, the services available, and its organization and structure (Reigada; Romano, 2018). In Maria's experience, this disbelief supported her decision to seek other

services. In addition, there was precarious care without the right to choose another healthcare professional in the public sector. In the case of pregnant women affected by Zika Virus infection, carelessness in prenatal care and limitations in the provision of services were observed, as most of them received a diagnosis about their child's health condition after birth.

“He doesn't have microcephaly; he was just born purple”: postpartum surprises, doubts, and pilgrimages in search of answers and care

Comparing José's birth experience with her other children, Maria considers that she had a humanized birth. For her, having her husband's presence during that moment was essential to feeling more secure in labor that lasted about five hours.

It was humanized; I felt safer because his father was with me [...] because someone was there to help me, right? (Maria)

For Maria, the idea of humanized childbirth permeates the fact of having a companion of her choice with her during the child's arrival. Such a fact did not occur in her previous deliveries. The companion's presence also ensured surveillance and care at birth of José. Her partner accompanied her, helping with labor and becoming a link between her and the healthcare team.

When I saw that it was being born, I said, look, it's being born, then João looked at it, and he ran and called, “it's being born,” and then three people came, then the doctor was teaching the other two. (Maria)

This points to the popularization of the use of the term “humanization” as a reference to healthcare/childbirth that minimally allows the woman/user of healthcare services to be an interlocutor, someone who receives attention but is also the subject of her care and not merely object/body of interventions. Humanized childbirth is not restricted to the father's presence in the delivery room. However, it concerns a set of good practices that range from

ambiance to the management of light technology protocols. By linking her partner's presence to “humanized childbirth,” Maria refers to the feeling of non-loneliness, of someone who looks at her, listens, and manages to trigger actors and actions perceived as qualified care, a recent experience in the SUS (Brasil, 2011).

The SUS regulation recommends that every pregnant woman have the right to access with dignity and quality care during pregnancy, childbirth, and the puerperium. Furthermore, it must be conducted humanely and safely (Brasil, 2000).

On the one hand, the term's popularization brings to light the possible relationship with its incorporation in a series of healthcare policies implemented in the SUS since the beginning of the 2000s. On the other hand, by doing so, it hides and restricts its inherent polysemy and history of disputes for changes in technical-assistance practices linked to discussions in the scope of law and gender relations.

Diniz (2005) traces the origins of the term in the scope of childbirth care and some of the polysemic meanings that the term “humanization of childbirth” acquires in the dispute, sometimes converging and sometimes contrasting, for legitimacy. Among these meanings, the one related to the “political legitimacy of claiming and defending the rights of women (children and families) in childbirth care” (p. 633) seems closer to the issues evoked from the story of Maria's life and the delivery of her child with CZS, as it refers to social rights, the provision of quality services, and the right to information and dignified and equitable treatment.

Based on Martin's (1989) analysis of reproduction, the female body, metaphorically, constitutes a factory for the production of healthy children under medical (power) supervision, leaving women with the role of “workers” alienated from their product in a clear analogy to the capitalist industrial mode of production.

Maria seems to have gone through many of these experiences in her reproductive life. It occurred not only in the (non)relationship with physicians but in the direct experience of the careless way of caring for her reproductive health. Not being informed

of the risk of a possible pregnancy while using oral contraceptives and antibiotics, and not being offered another effective method at that time, such as a maintenance-lacking machine, and when being mistreated by the physician's violent speech regarding her need to understand her son's illness, as if she were simply an unproductive factory.

They took him to clean, do the exams, and everything, and I asked the father on the way back: “- so, is everything ok with José? - All right, he doesn't have microcephaly; he was just born purple.” Then the doctor came and explained why he had been born purple, why instead of the crown of his head coming out, his face came out first, the front of his face. (Maria)

Difficulty in breastfeeding, crying, and irritability made that experienced mother activate her knowledge and question the diagnoses of “normality” presented to her whenever she went to see a physician. This fact demonstrated ignorance and disregard for the mother's complaints or the negligence of healthcare professionals who seemed out of context with the ongoing epidemic.

I said no! This is not normal”. Because he's my fourth child, none of my children showed it, neither nephews nor people I knew. To my knowledge, no child was like José. (Maria)

Access to a qualified professional who could provide an adequate response to her child's health condition occurred three months after birth.

It's when my mother heard on the radio that there would be a joint effort to diagnose children not only with microcephaly but with another type of pathology. (Maria)

This situation, despite revealing a late diagnosis and without many certainties, indicates the importance of the joint effort as a strategy developed by the State and Municipal Health Departments for the active search, identification, and diagnosis of cases by qualified professionals at a time of an epidemic of a disease still little

known and which, for this reason, could lead to underreporting of cases (Quadros; Matos; Silva, 2019). In addition to guaranteeing access to this child until then outside the care network.

Possible choices and impacts on the lives of families

Even after her son's diagnosis, Maria heard several professionals say they did not know how to deal with that child. Desperate for more information, she came to pay a consultation worth R\$ 600.00 with a neurologist in her city but was advised to seek more specialized healthcare services in the capital.

“[neurologist] indeed, here the tomography shows that he has microcephaly due to calcification.” He said that he didn't study it, didn't even know what to say, and indicated that I should look for a doctor here in the capital. (Maria)

The lack of knowledge of some healthcare professionals resulted in severe difficulties in the relationship and communication between professional and user during the consultation or at diagnosis time. Others had an aggressive and fatalistic speech, causing even more suffering and anguish for the parents, as expressed in Maria's speech:

On Tuesday, I had an appointment with José at the same hospital [...] with the doctor who was following up on the children with microcephaly, so he was very rude to me. It's when I asked him: Doctor, what is microcephaly? Then he said: it's a child born crazy, you'll never have a life of your own, that's what he said. (Maria)

This struggle in obtaining information from professionals led the mother to seek other sources, such as the internet and social networks.

[...] that was already March, then I started to find out and the internet, if you google it at the time, only the child with a small head and that black band on his face, covering his face, appeared. Then you get scared; you start to want to watch television, to want to look, then you just find absurd things. (Maria)

The uncertainties since pregnancy led Maria to experience mixed feelings, such as doubt, blame, non-acceptance, and abandonment. This brought up questions such as “why was my son born like this?”, “what did I do to deserve it?” On the other hand, they also evoked feelings of acceptance that led her, like other women in similar situations, to see him as a divine gift and to learn to know more about her child’s health/disease condition, what his needs and what health care/services are needed to provide him a quality life.

The ambiguity of feelings such as uncertainty, guilt, loneliness, overcoming, willpower, and determination, in addition to questions and explanatory possibilities for the occurrence of microcephaly/CZS, were also pointed out in other studies (Carneiro; Fleischer, 2018; Hamad, 2019). Carneiro and Fleischer (2018) use the expression social diagnosis to refer to the various explanatory possibilities (unexpected effects of vaccines or medications, problems with childbirth or pregnancy, and explanations related to religion, for example) as a counterpoint to the publicized scientific diagnosis of the causal relationship with vector transmission of the virus.

Maria’s routine is full of challenges, struggles, and much fatigue. She seeks several coping strategies, and faith is one of the most important in accepting her child’s health condition and maintaining her psychological balance.

Authors such as Pimentel (2018) and Melo et al. (2020) emphasize that the public health emergency brought, for these mothers, an urgency to redefine their maternal place. There was no time for mourning the imagined child, motherhood is highlighted as a gift from God, and children are sacralized as “angels” who bring teaching to life. Religion becomes an encouragement for these families in the search for comfort and, as highlighted by Melo et al. (2020), the transcendental is used as an explanatory/interpretative resource for changes in life in the face of the most pessimistic prognoses found in the media or made possible by healthcare professionals.

Due to the delay and difficulties in accessing healthcare services, the child started rehabilitation procedures at almost one year of age. There were

many challenges because these procedures were only available in the Metropolitan Region of Recife, leading the mother and child to travel from the countryside to the capital several times a week. This reinforces differentiated and unequal access for those who live in cities far from major centers.

That’s when I decided to live here, then we came here, and that’s when it got better. The real quality of life was when we came to live here in Recife, and people and doctors treated us like human beings, not like animals. (Maria)

The feeling of loneliness that many mothers feel at various times in their lives in caring for their children can be alleviated through contact with other mothers who live in a similar situation. In the exchange of experiences, they feel more understood and encouraged to face the challenges they face in caring for children (Pimentel, 2018).

Maria’s encounter with institutions that support families of children with CZS was of paramount importance so that she could take ownership of what was happening, empower herself concerning her and her child’s rights, and identify which healthcare services she could seek and try to enroll him.

In July, when the association met, I got to understand what microcephaly was and that all children were different from one another. Some walk, those who walk/talk, there are those with one side more stagnant than the other, and there are, really, those who are vegetative, taking several medicines a day to try to control the crisis. (Maria)

Contact with other mothers via social networks promoted the exchange of information and psychological support, also serving as an escape valve for everyday stresses (Pimentel, 2018). From this contact, the mother got access to a philanthropic institution that sought to stimulate the child’s development. However, after a year of treatment, he was discharged from the service because he did not develop as expected.

Early stimulation is the recommended treatment for these children, and the sooner it is started,

the better for their motor, sensory, perceptual, linguistic, cognitive, emotional, and social development (Peiter; Pereira; França, 2020). Pilgrimage to these services has been a common experience among families affected by CZS (Albuquerque et al., 2018). The discharge from the philanthropic service led the family to seek physical therapy care through the healthcare plan, which also canceled appointments after a certain period.

Private healthcare plans tend to limit the supply of services, and most of the charges (fall) on the SUS which, due to problems with lack of funding or underfunding, sharp dismantling and scrapping as of Constitutional Amendment No. 95, combined with the fragmentation of services, lack of continuing education, and unpreparedness of care networks, cannot respond to the population's demands efficiently and effectively (Paim, 2018).

Peiter, Pereira, and França (2020) point to the need for constant care that these children need and the importance of accessibility to specialized services for treatment and rehabilitation, which are crucial for their development. The recommended would be treatment and rehabilitation units that offer all the care they need, as close as possible to their home. This would avoid the physical and mental exhaustion of the child's mothers/caregivers, who live in a constant search and wait for these services, in addition to not having to travel to different places to receive the care.

Brazil's public health situation with the epidemic in 2015 and 2016 brought the need to restructure the care network to meet new demands quickly and continuously (Mendes et al., 2020). Despite it, the healthcare system was slow to reinvent itself, and on many occasions, mothers of children with CZS felt unsupported, lacking responses, and unattended.

If there weren't so many waiting lists... [...] I've been on the waiting list for two, three years [for a reference care service] with José and never, ever [they called], I think the papers are filed there, as I was never called for anything. (Maria)

When asked about the future, Maria prefers not to think; she waits for things to happen, the result of many frustrations.

When I think about the future, I get a little desperate because I see José bigger. If I think about José in five, ten years, it gives me butterflies in my stomach, you know. I say: hey, he is only five, and I already have difficulty bathing him, I already have difficulty with that, the treatments for him are already difficult, the consultations are already difficult, imagine from here, then I stop, I say, no, I'm going to stop; otherwise I'm going to freak out. (Maria)

Although Pimentel's (2018) study shows that most mothers yearn for their children to walk, talk, and respond to stimuli, Maria chooses not to think about or express such yearnings. The fear of the unknown makes her not create expectations about the future. It is the result of many "no's" and disappointments that have accumulated along this journey with her child. Additionally, the COVID-19 pandemic has reactivated memories of the Zika epidemic, the suffering faced, and the fear of losing her son.

Despite the difficulties, Maria says she does not stop having fun and goes to leisure spaces with her child and her partner. Despite feeling the need to have some time for herself, she cannot leave her child with a caregiver because she does not trust them; she is afraid that something terrible will happen and feels guilty, believing that only she knows how to take care of him.

Some studies have highlighted the centrality of maternal care and the difficulty of sharing care with others. This occurs either because of the misunderstanding of how exhausting this form of care can be or because of the lack of confidence in other people performing these activities (Vale; Alves; Carvalho, 2020). This form of behavior and feeling of responsibility centered on mothers is linked to what Badinter (1985) called the "myth of maternal love," evidencing how the attribution of roles and responsibilities for care to women/mothers, far from expressing a supposed feminine nature, results

from social functions constructed and also mediated by hegemonic medical philosophical and political discourses throughout history.

This journey has been tricky daily. Since José was born, the barriers faced in healthcare services, society, and the family have been challenging. Although particular to Maria, José, and their family, these results illustrate in detail the context similarly shared by other women who had a child with CZS, to a greater or lesser degree.

This points to the urgent and late need for reorganization in the supply of healthcare services, putting into practice the principle of integrality and the decentralization guideline, given that most medium and high complexity services are located in the Metropolitan Region of Recife and that the focus of care in these cases has been centered on children, sometimes neglecting the needs of women and their families.

Final considerations

Despite the seriousness of the country's health situation requiring quick and multidisciplinary responses from the healthcare authorities, the emergence of a disease unknown to the scientific community highlighted a series of difficulties that the SUS has in meeting the population's specialized health needs, reverberating in care for women, especially those in poverty, and children with disabilities.

The CZS epidemic revealed problems beyond mosquito vector control, revealing deep structural inequalities concerning access to health information and communication, sanitation, assistance, and access to quality public services, among other aspects directly related to the social determinants of health of life territories.

The current scenario reveals the vulnerability of this population as children with CZS. In addition to presenting various health problems and needs, they may have had their development more affected by the emergence and consequences of COVID-19. This has further exposed some of the weaknesses of the healthcare system and how important it is to maintain an articulated and resolute healthcare network both in comprehensive care and in health surveillance.

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Authors' contribution

All authors contributed effectively to the construction of this article.

Alves contributed with the methodology and original draft writing. Melo contributed with supervision. Alves and Melo contributed to the conceptualization, formal analysis, and investigation. Melo, Valongueiro, and Santos contributed with writing, review, editing, and validation.

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