Facing a new reality from the Zika Virus Congenital Syndrome: the families' perspective

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Abstract This paper presents the partial results of the research on the social implications of addressing the Zika Virus Congenital Syndrome (ZVCS). This study aimed to analyze the repercussions of the diagnosis on the life of the families attended at an Institute of reference in Rio de Janeiro, based on a qualitative study built on the thematic analysis of the data collected through semi-structured interviews with 15 mothers from October 2017 to June 2018. The results revealed the helplessness of families and health professionals faced with the revelation of an unprecedented and challenging diagnosis, the lack of a structured referral and counter-referral network in the care of children when newly diagnosed, the imposition of an exhaustive care routine, generating social isolation, exhaustion and overload of these women, and the difficult access to public policies. Among the primary resources to cope with these adversities were the religiosity and articulation with other women who experienced the same situation.

Key words Child, Care, Public policy, Zika

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Introduction

In the second quarter of 2015, Brazil was faced with an unprecedented and troubling situation: the unusual multiplication of children born with microcephaly and other fetal malformations, whose etiology was hitherto unknown. We were faced with what later came to be diagnosed as the Zika Virus Congenital Syndrome (ZVCS), transmitted by the same dengue and chikungunya vector. It was an unknown presentation of the Zika virus in humans, with severe vertical transmission repercussions whose biopsychosocial, political, and economic implications were unknown. An emergency public health situation emerged in that context and imposed a set of needs: to produce knowledge, structure care, and prevent new cases. Different national and international institutions produced a set of efforts to face these challenges, among which, as of 2016, a clinical research cohort was established in an Institute of reference in research, education, and healthcare in Rio de Janeiro, to understand its implications, in parallel with the provision of care to children and their families.

A research project linked to this cohort was created, and articulated education, research, and healthcare in the analysis of addressing with the adversities brought about by the syndrome, based on data triangulation, collected through the analysis of medical records, participant observation, and semi-structured interviews. This paper presents the results of the semi-structured interviews, which sought to establish an approximation with the viewpoint of the subjects who have been addressing the experience of providing the daily care of children affected by the Zika virus.

In light of the theoretical production on the syndrome within social sciences and health, we aimed to apprehend changes and impacts of the diagnosis in these families' lives and the resources triggered to face this experience. We assumed that the syndrome is a complex chronic childhood health condition¹, with limited physical or mental functions, medication, dietary, and technological dependence, requiring rehabilitation therapy and multidisciplinary care, and that this experience is traversed by societal contradictions, which are expressed in power asymmetries in the gender, social class, race, and generational relationships². By placing the ZVCS in this context, we refer to a chronic health condition that brings severe impairments to the neuromotor development of the affected children³ and demands a set of health goods and services accessed with essential constraints. The syndrome also imposes a reflection on the experience with the disability and predominance of a biomedical conception that perceives it as an abnormality and relegates to the "background a complete conception of a social model of disability, which conceives it as a bodily form of being in the world"4.

In this scenario, the construction of childhood and motherhood concepts builds on the set of possibilities for understanding the social processes that cross the lives of these children and their families, where "being in the world transcends the experience of receiving care daily by health professionals."4

Costa⁵ signals the hegemony of the biomedical vector-centered approach to understand the effects of exposure to the Zika virus, to the detriment of its determining social processes, which contributes to "diluting" the state's responsibility for the epidemic and its consequences, with its subsequent naturalization. Understanding the social processes in which the ZVCS is inscribed presupposes, therefore, knowing these families' living conditions, their access to services, and infrastructure⁵. Silva et al.⁶ suggest that the state's discourse has focused on the search for technologies for mosquito control, social mobilization, and the construction of integrated actions, to the detriment of reliable support for children and their families, whose budget is highly affected by the needs brought by the chronic illness in childhood⁶. These need to bear the social and economic weight of the epidemic, mobilizing a political and economic field in which the loss of formal employment intensifies the lack of resources of these families7.

The hegemonic nature of the biomedical and mosquito-centered approach to the epidemic has been accompanied by a public image in which the mother-child dyad predominates, reaffirming parenting models in which women are identified as unique caregivers8, which barely converges with the agendas of the feminist movement or the debate on care and the gender division of labor. Thus, the historical association between the overvaluation of motherhood and practices of care, love, dedication, and sacrifice is reproduced4. This scenario gave rise to a movement of women/mothers focused on the public recognition of the needs of children and families affected by the ZIKAV, establishing associations geared to the fight for rights, whose relationship with the state has been configuring an arena of unequal disputes⁶ and is the culture broth in which families/ women individually face the experience of caring for children severely affected by the virus, whose analysis is proposed below.

Considering the experience of families in the process of illness and treatment for the Zika virus congenital syndrome as a crucial mediation for the construction of knowledge on this theme, we aimed to analyze the elements interacting in their daily lives and are directly related to the care process. Based on the understanding of the "rationalities" (herein understood methodologically, and not ontologically) moving the subjects, we investigated the main limitations and potentialities inscribed in the experience with illness by ZVCS. That is, considering communication, located in time and space, as something that complements men given their finitude9, the idea was to explore the statements of these families located from the context in which they were produced and identify the challenges and potentialities in this experience. Thus, we proposed to explore the fields of possibilities in which these subjects are located¹⁰ and identify the space open to the formulation and implementation of their projects, a space resulting from the interaction between the socio-historical process and its interpretative potential of culture's symbolic world of culture¹⁰.

Methods

This is a qualitative study conducted by content analysis from the thematic perspective^{11,12}. The reports on the paths of chronic illness in childhood in these families' lives emerged from the experience of 15 women serviced at the Institute, who participated in semi-structured interviews, from October 2017 to June 2018. The roadmap consisted of open questions focusing on the care path undertaken until reaching the Institute, discovering the child's diagnosis, the changes that have taken place in the lives of families since then, the difficulties, and the resources employed to face these difficulties.

The statements were transcribed in full in the pre-analysis phase, allowing for a free-floating reading of the collection. Then, each interview was read, and the empirical material was organized. The second phase (coding) consisted of the detailed analysis of the selected material and data coding from the thematic units, enabling description of the manifest and latent contents. Then, the thematic categorization was performed, based on the grouping into meaning cores, taking as reference the similarity of contents in the subjects' statements and the theoret-

ical framework of the research, from which the following categories emerged: 1) the discovery of diagnosis; (2) the social implications of ZVCS; (3) facing a new reality from the diagnosis.

The study fully met the ethical requirements of Resolution N° 466/CNS/12 and was approved. The participants' statements were identified by the number of interviews to preserve their identity.

Results and discussion

While there was no previous gender selection, all respondents were women and mothers, reflecting the historical female responsibility for the family care of people with chronic illness. The mean age of these women was 27 years, most had at least a secondary school level, and three had higher education. Nine respondents used the Continuous Cash Benefit (BPC), which secures a monthly minimum wage to older adults and people with disabilities, provided that the criterion of per capita monthly household income of less than a quarter of the minimum wage is satisfied. Although we are unaware whether it replaces the losses caused in the family budget, its use by the respondents corroborates its importance in addressing the adversities imposed by chronic illness in childhood, even considering the restrictive income criteria of the benefit and that does not generate social security and labor guarantees for these female caregivers.

Joining the Health Network

The public health emergency installed since 2015 brought the need for emergency service structuring, without having enough time to plan actions and organize a flow of care in the service network. In this context, in general, the families that participated in the interviews joined the Institute of reference in which research was carried out through informal networks, active search, and capture of clinically more complex cases in other health units. Given the public health emergency scenario, the Institute made its access criteria more flexible and established a different gateway for children with ZVCS, who were immediately received, evaluated, monitored, or referred, according to the diagnosis, without further bureaucratic requirements or linkage to the regulation system. Thus, the articulation between research and health care was fundamental, where part of the structuring of care was financed by

research resources, in the same way that it was necessary to produce knowledge about that new health condition so that qualified and necessary care was offered.

[...] you didn't have Zika, her father didn't have Zika, but the way you're telling me, the doctor who sent me here ... they were exactly looking for the child's aspect to research the disease. (Dep. n. 13)

If the reference centers had their doors open to receive these families, the respondents believe that their arrival was random. In the absence of a previously structured flow, the internet and the experience of other mothers found in the corridors of health units, were the primary sources of information and guidance regarding access to treatment, despite the dispatch of Interministerial Ordinance 405¹³, of March 2016, entitled "Strategy for rapid action in the fight against microcephaly", to promote the identification, evaluation, and care of children with a suspected case of Zika virus infection.

[...] I became friends with a girl who was also hospitalized with her daughter. So, she said that it was perfect here that everything was right here: all the child's required support. Then I asked her if she could see with the doctor whether he could fit me in. Then she saw a doctor, and she told me to come. That's how I got here. (Dep n.08)

The absence of care support reported concerning access to necessary treatment was not restricted to the care flow, as we will see below.

The discovery of diagnosis

In the interviewed families' universe, the diagnosis was discovered in two distinct stages: during pregnancy or in the postpartum period. In both cases, the helplessness shared by families and health professionals concerning the lack of diagnosis was highlighted, since we were faced with the first generation of pregnant women infected with ZIKAV in Brazil¹⁴.

[...] I made an ultrasound, and I found out I was pregnant. Then, as soon as I found out, I started doing prenatal care at the clinic, where I live. Five months later, the ultrasound was all right. From five to six months, the US showed a small head; her fist was crooked. So, I commented that I had been infected with Zika at two months into the pregnancy. She went and asked for another ultrasound. Another month passed to see if her little hand was still crooked, and the head was small. Then, she went and said to me that it could be a risky pregnancy and stuff [...] (Dep n. 09.)

The discovery of the diagnosis coincided with the first research efforts in the face of the Zika epidemic. The families were helpless with the coming of a child diagnosed with a chronic disease barely understood scientifically. The uncertainties regarding the future and the children's development were issues set out there and tended to deepen, in some cases, due to the problematic diagnosis: when he was born [...] they told me he was a suspected case. I only had confirmation after two months (Dep. n. 01.). However, confirming the diagnosis is not always sufficient to understand these uncertainties, as shown in the report below, highlighting the daily experience of concerns regarding the child's development:

I don't know ... if someone comes up to me and asks [...] if the baby has microcephaly, what part is going to be done, I will not be able to explain. I honestly don't know until to this day. It's because they explain that he [...] had microcephaly and is developing well [...] But I don't know which phase was reached, or which was not, what will be affected and what will not. So, I won't be able to explain because I don't know much either (Dep. n. 13).

Families gradually implemented the association between fetal malformations identified in imaging tests during prenatal care and an epidemic that terrified society. In some cases, the initial identification of fetus hydrocephaly brought, for some time, the expectation of a more "comfortable" diagnosis, since it would not be related to a previously unknown disease, with an uncertain prognosis. In many statements, despite changes in imaging tests, this diagnosis was only confirmed after the child's birth.

[...] When I had a neighbor there, he had this disease, hydrocephaly. With the operation, he put the valve on: he walked, spoke... a healthy child. So that comforted me. When it came to Zika, things were more restricted. However, we learn to love each day and understand the disease. Accepting many things... Now I'm an expert at it. It is much easier now (Dep. N. 04).

The respondents' reports suggest a relevant difficulty for health professionals in communicating a diagnosis that would seal the fate of those families: "When she was born and I was getting stitches, the pediatrician came up to me and said: 'your daughter has microcephaly'. Just like that. He just said that she had microcephaly." (Dep. n.7). Although we were faced with an unprecedented situation, the communication of difficult news in the immediate postpartum period, while under procedures, without any preparation or clarification calls for future questionings.

The account of this other mother, who reported having discovered the child's diagnosis from reading the live birth declaration, corroborate the need for reflection on the qualification of health professionals to receive these families and, more particularly, the communication of hard news.

[...] this diagnosis was not given by the doctor. It was written in the live birth certificate that we need to register in the registry office. There was a section for congenital diseases, which was completed with the word "microcephaly". Then I had the real notion that this was my son's problem, who until then had done all the prenatal care sessions, I delivered the baby correctly, but this diagnosis was never informed. Until then, he had a larger head than the standard, and edemas, that's all (Dep. n. 08).

Afonso and Mitre¹⁵ affirm that difficult news changes people's perspectives on the future, bringing a sense of loss of control over events and a change in priorities. In this context, illness often takes center stage in the lives of people or families. Baile et al.¹⁶ indicate that this news is the starting point for a new family reality, fraught with new needs and uncertainties. The way this communication is performed can interfere with people's or family's relationship with the disease and treatment¹⁵.

The communication relationship between the subjects - health professionals and users affects the disease's perception and the possible therapeutic project¹⁷. Communicating is a light health technology, that is, within the scope of relational and dialogical practices that act as fundamental mediators in the relationship established between the health team and the user/family, whose role is fundamental in the construction of the health care process. Thus, besides the perplexity brought about by an unprecedented and complex diagnosis, these reports suggest the need to deepen and expand the discussion on the communication of difficult news within the scope of the Unified Health System (SUS). When analyzing the experience in Recife, Carneiro and Fleischer¹⁸ signal the absence of support to and reception of women in communicating the diagnosis, led to seek alone the meaning of what would become ZVCS, on the internet, at home, and on social networks. The authors argue that, while the subject is hardly known by biomedicine, nothing seemed to "justify how women were communicated and, after diagnosis, so poorly accepted"18.

The social implications of ZVCS

While pregnancy has not always been planned or even idealized by families, in general, in our society, initial expectations regarding the birth of a child tend to orbit around the idea of a healthy baby. Confronting the diagnosis of ZVCS presupposes addressing a new reality, both concerning its affective aspects and specific issues, such as the pilgrimage through different services in search of care, the reconfiguration of life projects, coping with stigmatization and, above all, the idea that the child will have a different development from the others.

I was sad, upset. Because it was a planned pregnancy, it was not accidental, both father and the mother wanted it. Furthermore, for me, it was a shock when I found out [...] So, it was a change. I didn't expect it; it was a punch in the stomach, as my husband used to say. However, I think God prepares us because I preferred not to suffer, not to cry about it from the beginning (Dep. N. 9).

Dealing with such a complex and little-known diagnosis during pregnancy and immediate postpartum implies overlapping the family's adaptation to the arrival of a new child, which, in general, already interferes with sleep and rest schedules, adapting to the reality posed for diagnosis. In this sense, it is essential to point out that, according to Eickmann et al.¹⁹, one of the signs that make up ZVCS is irritability and excessive crying, which was pointed out as a stress factor by one of the respondents, leading to exhaustion of continuous care. *It was too bad to sleep. I didn't sleep at all. I stayed awake for fifteen days* (dep. 13).

Within this perspective, social interaction was another aspect of the change in family routine that emerged impactfully. Social activities tended to be drastically reduced due to the impossibilities imposed by care, leading these women/mothers to home confinement, which was aggravated in the absence of a support network and sharing of care. Due to limited time to perform other activities, the person responsible for the care, who tended to be the child's mother, in the analyzed group, ended up isolating herself from social, cultural, and leisure activities.

After he was born, it was just he and me. There were many changes. Many people walked away. It's just me, and he is going to the doctor. Things changed a lot, literally (Dep. n. 12).

I have to have much time for her, and things are for later. I don't leave the house anymore, and I don't go to church at night (dep. 11).

Scott et al.4 suggest that ZVCS "raises care for others to a life motto, imbuing this care with ideas of sacrifice and ambiguous self-depreciation". The authors argue that using the positivity of maternal dedication is a critical symbolic resource before an uncertain future, permeated by obstacles. Besides these symbolic elements, confirmation of the diagnosis brought about a real change in these women's professional lives. They stopped working altogether to care for the children, precisely when family expenses with health increased, which is validated by Looman et al.20, who address this issue concerning chronic illness in childhood.

I can't work anymore nowadays because I have to do his treatments. No one will want to hire a person who will live more at a doctor than at work (Dep. n. 3).

According to Cunha et al.21, several changes occur in the family routine after the diagnosis, requiring more time and dedication in assisting the chronically ill child, leaving aside other tasks. This new reality points to an essential burden for these women, who take full care of the children and become invisible in their suffering, pressured by a naturalized role linking motherhood to care, selflessness, sacrifice, and mission.

I have three children with her. I don't work. I didn't work anymore because I was already unemployed and separated from her father. So, [...], it was a massive fight in my family, because [...] no one supported or helped me. So, it radically changed my life. Radically, everything changed (Dep. N. 8).

Although almost all families were nuclear, women were the main responsible for the children, given the cultural tradition that links gender (female) and care, which is aggravated in hospital admissions and outpatient visits²². The lack of public policies to support workers, whether under Consolidated Labor Laws (CLT) or informally, with dependents in a situation of chronic illness, places this care in the field of employer-employee solidarity rather than guaranteed right. Culturally, the absence of women at work to provide hospital care for dependents tends to be more tolerated than that of men, as is the risk of job loss. Likewise, the sharing of childcare and support for families is predominantly carried out by other women:

[...] I can count on her in this case. She is my neighbor, and stays with the child, so I can prepare meals, sweep the house, fix things that need fixing. My mother-in-law also helps me. My mother lives nearby (Dep. n. 7).

The inclusion of children in the education policy is a crucial element for reflection, given its relevance for social inclusion and stimulating development and its potential to contribute to the reorganization of the lives of these families. However, this perspective tends to be severely affected by chronic involvement. In general, families feel insecure about sharing their children's care with institutions that may not be structured enough to receive them.

So, from pre-school to daycare, I think that someone specialized should be at the daycare to attend this type of child, not only with microcephaly but with other disabilities. Not everyone can do it. I think there should be qualified people in the school area (Dep. n. 13).

Addressing the development of children with ZVCS, the fundamental role of early stimulation in exploring and developing children's abilities is highlighted, contributing to their physical, cognitive, neurological, social, behavioral, and affective development. At the peak of the epidemic, in 2016, the Ministry of Health built the Guidelines for the early Stimulation of children aged zero to three years with neuromotor development delay²³.

The document was a strategic action of the National Plan to Combat Microcephaly²⁴, and guided actions and multiprofessional health teams towards the care geared to this audience, addressing themes such as the assessment of visual, motor, auditory, cognitive, and language development, the use of assistive technology, early stimulation, the importance of playing, and the active participation of families.

Despite public recognition of the importance of early stimulation, access to multidisciplinary care in rehabilitation is still a vital hurdle experienced by families:

[...] it is challenging to have a daughter with special needs and not perform the treatment. She doesn't do physical therapy because there is no way to do it. There is no vacancy where I live, only down here. Furthermore, I cannot come because I don't have the money to pay for the bus ticket (Dep. n. 08).

The epidemic was installed in the country at the time when the State's counter-reform was deepening, affecting the social security expenditure limits, with the consequent insecurity, scrapping and, even shutdown of health and rehabilitation services. An essential part of care was structured in specialized institutes in conjunction with research projects, with no guarantee of continuity beyond the initial deadlines.

Three years into the epidemic, relevant difficulties in ensuring the comprehensive care of children with ZVCS are still observed, including

access to anticonvulsants, wheelchairs, and commuting to services.

[...] My daughter doesn't do speech therapy. Physiotherapy only takes place once a week, and it is here. I live 54 kilometers from here, so it is very complicated. [...] The Continuous Cash Benefit (BPC) was also denied because I worked, I had a tax number for an individual microentrepreneur. So, I'm in my fourth lawsuit against Social Security (INSS), awaiting rulings to see whether the benefit is released or not. So, help comes from the family, even to buy medicines. Sabril costs R\$ 297 reais, and we use two boxes a month. So, one gives 50; another gives 100: there is always someone helping (Dep. n. 10).

Commuting to health services, and especially reference institutes, which tend to be more distant from the families' place of residence, is not something that happens without difficulties. The insecure provision of adapted public transport is added to the need to use more than one means, in most cases, and the need to carry out more than one registration for a free pass. The metropolitan region of Rio de Janeiro currently has about three different free passes (municipal, intermunicipal, and subway passes).

Theoretically, children living more than 50 km away from the place of their treatment would be supported by Ordinance N° 55, of February 24²⁵, which defines states and municipalities' responsibility to ensure access to treatment in other municipalities or states, when necessary. However, when this right is guaranteed, significant difficulties are reported concerning this service, both due to the absence of adequate vehicles and waiting time of mothers and children in health units until the cars leave, which tends to take hours.

Concerning transportation, nowadays, everything is with the Health Department. They sometimes use the Doblô, sometimes we go by bus because they say they never have a car, and we have to come at dawn, but we only are attended in the afternoon, or seen in the morning and have to stay until late, and only come home at night, waiting for other patients (Dep. n. 06).

Facing a new reality from the diagnosis

Considering the social implications described above, we aimed to analyze in the statements some resources for coping with the adversities brought by the diagnosis. Three elements stood out in the statements: the articulation with other women and political mobilization, religiosity, and the relationship with health services.

In the context of an unprecedented disease, the consequences of which were still little known, communicating with other families who were experiencing the same situation allowed exchanging information and articulating the struggle for rights. This mobilization was initiated on social networks and sharing media, extended to face-to-face meetings, acts and public hearings, and legal actions to access medicines and other resources. Meeting other women who were going through the same experience and the mothers' movement, is pointed out by the respondents as an element of individual and collective strengthening.

I want to contribute, help other mothers that I know who, unfortunately, will still get there. So, they have a little sense of what it's like. I participate in the mothers' movement: it has been an excellent knowledge for us mothers. We gather every Thursday there. So, we are practically pioneers. Then, I exchange with all kindness and love, because I think it's essential. I think that any help at this time is very welcome (Dep. n. 01).

Moreira et al.⁸ highlight these women's mobilization as an element of "transit between personal pain and collective causes, suffering and rights, and different forms and dimensions of mourning" while emphasizing the collective dimension of health inequality.

Religiosity is an element of confrontation with ZVCS that is also present in the statements. Aquino and Zago²⁶ argue that religiosity plays a vital role in healthcare contexts and coping with illness processes, which is not very different in the interviewed families. Answers to the birth of a child with such health problems are sought in this field.

So, it was a change that I didn't expect, it was a punch in the stomach as my husband used to say, but I think God prepares us because I preferred not to suffer, not to cry about it from the beginning. I left the crying for him... I respected it because he said: "I need to do this". So, I said: "I need strength because she is still inside me". I needed to pass on this love that I already had. So, it had to be even greater. My concern was this. [...] When she was born, I was already prepared to receive her, so I prepared my house, my family, talked to everyone. Everyone understood, and she is this very loved and accepted the child. I had no problem with acceptance (Dep. n. 01).

Although institutional relationships in health services tend to be vertical and asymmetrical, guided by a Flexnerian paradigm, which fragments the health needs of the population in specialties that do not always dialogue with each

other, one of the respondents identified the relationship with the Institute of reference and health professionals as a resource to face the adversities brought by ZVCS:

[...] I find support here [at the Institute of reference] of these people who care for her, with a lot of love and affection. I think that she is very dear wherever she enters. [...] It's not just being a doctor, going over there. There's touching and asking. However, we see the dedication and affection of doctors here. So, this is what I like to be here for. It is difficult, but I feel good here because I know that I am well accepted, and my daughter is well accepted (Dep. n. 01).

The statement above corroborates the importance of building horizontal relationships between health professionals and service users. The guarantee and preservation of care spaces, where families feel well accepted and respected, contribute to coping with the adversities imposed by chronic illness in childhood.

Conclusion

This paper aimed to analyze the experience of a group of women who face the daily challenge of providing care for children affected by ZIKAV, a complex chronic health condition whose recent emergence deepens the uncertainties and adversities faced. Part of these uncertainties is situated in the general scope of the problems inherent to chronic illness in childhood. Others refer to the particularity of a disease hitherto unknown, whose clinical, social, and political developments unfold gradually over time.

In this scenario of old and new uncertainties, the difficulty of access to public policies, the need to discuss the relationship between gender, care, and gender distribution of work, and the need to expand the debate on the preparation of health professionals for receiving families, especially when news that will seal their fates are being announced.

If the adversities faced by these families are enormous, the resources mobilized to face them are also significant. Among these, the sharing of experience with other women stands out, through which they seek some collective understanding of the process they are experiencing and the equation of public demands.

Collaborations

AG Mendes participated in the paper's conception and design, elaboration of the methodology, literature review, data analysis and interpretation, and final drafting and critical review in its various stages. DS Campos participated in the paper's conception and design, elaboration of the methodology, analysis, and interpretation of the data and final drafting of the paper. LB Silva participated in the paper's conception and design and final drafting of the paper. MEL Moreira and LO Arruda participated in the review of the paper.

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