Send it to one, throw it to another: the Zika health emergency on the margins of the State

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Abstract: Temporarily distant from the declaration of the Public Health Emergency of International Importance (ESPII) and Public Health Emergency of National Importance (ESPIN) caused by the Zika epidemic, in 2015, we enunciate the legacy of the humanitarian emergency. Based on qualitative research, through focus groups with health professionals and families of children affected by the Zika epidemic in Natal and Feira de Santana, we seek to discuss this public health phenomenon through the lens of State Anthropology. We conclude that the non-recognition of the State as an instance embodied in the daily practices of its local agents leads to the reproduction of discriminatory practices emptied of political sense and the recognition of moralities that permeate the absences in health promotion actions and recognition strategies, and search for methods to guarantee the right to health.

Keywords: Public health emergencies. Zika epidemic. Anthropology of the State. Microcephaly. Child health.
Configurations of the Zika epidemic for an Anthropology of the State

This article was written seven years after the declaration of a public health emergency of national (ESPIN) and international (ESPII) importance caused by the Zika epidemic in 2015, and, therefore, it is urgent to demarcate this writing in time. The symbolism accompanies the idea of urgency that something concerning the emergency can signify greater alert. The warning is not to forget, erase, dememorialize the suffering, indignation and needs created by a particular group of women and their families, who experienced Zika-V infection during pregnancy, with repercussions hitherto unknown to science, by health professionals and the general population, among mosquitoes/viral infections/microcephaly in babies.

We will assume the expression microcephaly/micro, recognizing like other researchers (Fleischer; Lima, 2020; 2021; Pinheiro; Longhi, 2017) as part of the universe of people directly involved with the care of micro children. Microcephaly is related to the visible expression of changes in the head, which babies, today children aged 6-7 years, developed in the fetal period, from congenital Zika-V syndrome (SCZV). The change in the head, visible to others, is one of the most central stigmas of the congenital Zika-V syndrome (Moreira et al., 2022). But what escapes the eye and affects different systems and functions of the children's organism – creating multiple dependencies and needs for support and vital technologies – refers to its understanding as yet another chronic, complex and rare health condition, whose needs are also complex (Moreira et al., 2019; 2017; Moreira; Mendes; Nascimento, 2018).

The birth, configured existence, of children with complex health needs, meets a scenario of persistent inequalities not faced by the Brazilian State. Therefore, there is no democracy in epidemics and pandemics, but, as total social facts (Silva; Matos; Quadros, 2017; Santos; Pontes; Coimbra Jr., 2020), they reveal overlaps between sanitary and economic conditions, structures of discrimination referred to race, gender, class and territory, which can be stated in light of structural violence. Violence understood as negligence or “abandonment”, or “pushing games”, on the part of the State and its agents, when we analyze health phenomena, focusing here on the Zika-V epidemic that Brazil experienced between the years 2015 and 2017. It was responsible for affecting the population in the same period of circulation of a vector prevalent among us – Aedes aegypti – which also carried dengue and chikungunya.
These “pushing games” take on the connotation of abandonment, of the non-availability of services and attention to the minimum needs to guarantee the quality of life, appearing as an emic expression for sons and daughters living with microcephaly. The expressions are full of emotions and performances that already announce the need to fight to achieve, or advise by social service workers to search “for justice”, “for rights” and Souza-Lima (2013, p. 11, free translation) alerts us for the polysemy of the word right, which:

[...] contains, among other meanings, that of the set of established norms of conduct that guide social relations, marking right and wrong, good (for some) and evil (for others). In its plural, the term also points (along with duties) to the system of obligations and prerogatives that prescriptively translates such norms at the individual and collective levels.

At stake are the universe of subjects’ beliefs that they have rights to rights. It is questioned in their constructions about who has rights and who are the agencies and agents of these rights. Souza-Lima (2013) also highlights that rights are configured as a category of mediation/communication between social spheres. And in this set:

[...] emotions, feelings and affections circulate and intertwine in institutions such as the Police, the Legislature, or instances of the Judiciary, in short with what concrete social actors also call the State, here not only taken as a scientific concept, but also the category of those researched spoken and articulated via the fight for rights (p. 12, free translation).

At the level of Law, generic actors such as children, adolescents, women, citizens are mentioned. This generality needs specifications, when the State’s active violence kills, or when, by failing to do what it has to do, it also exterminates due to lack of access to healthcare with exams, medicines, and treatments. The exuberance of actions that make up health judicialization processes operates as an indication of what Viana (2013) calls “grammars”.

Between 2014 and 2018, more than 800,000 new actions involving public health were filed in Brazilian courts, most of which were drug requests against the State (Ferraz, 2019). This path of ideas, prevalent in our research collection, and present in many other research generators in “Zika scenes” (Silva; Matos; Quadros, 2017; Scott; Lyra, 2020b), gains recurring configurations: (1) a search for peers who share this experience and who meet in service waiting rooms, and organize WhatsApp groups for exchanges and support; (2) the organization of associations where women with the capital of education or vocalization of struggle become charismatic leaders, also sharing this motherhood crossed by the SCZV in their sons and daughters;
(3) individual actions against the State demanding access and guarantees of rights – education, health, services, care goods such as diapers, medicines, nutritional formulas – with the mediation of health and social service professionals, in health institutions with the preparation of substantiated reports.

We highlight here the tension between the plans for children’s rights to health – and currently to education at school age – and a State that is supposedly absent, although it institutes regulations that make plans for children’s care, subsistence and life unfeasible. This reported absence – or corrective and blaming the presence of the affected population, or even regulations that make benefits for income composition unfeasible – is read by the authors of this article as a set of symbolic violence that takes the form of negligence, blaming and abandonment.

One question guides this article: how can the Zika epidemic be interpreted considering the discussion about social suffering in the relationship with State agents?

**Methodological crafts or on group conversations**

As Gondim (2003, p. 151, free translation) reminds us, the “unit of analysis of the focus group [...] is the group itself. If an opinion is outlined, even if it is not shared by everyone, for the purpose of analyzing and interpreting the results, it is referred to as that of the group”. We assume the perspective of an exploratory focus group, dedicated to the production of content, generating hypotheses intertwined with theoretical perspectives, and being able to contribute with other plans of ideas, interpretations, needs and expectations.

The interactional component is a highlight when choosing the focus group, since what is at stake is intersubjectivity. But there is something that circulates and can build a common plan, based on a meeting with delimited objectives and whose participant profile evokes at least some shared identity aspect: in this case, two groups with family members and two with professionals. The focus groups of professionals were made up of nurses and social workers in Feira de Santana, and nurses, doctors, and nutritionists in Natal. Two researchers coordinated the groups held in August 2018, a woman from Feira de Santana-BA and a man from Rio de Janeiro-RJ, respectively, a nurse and a social worker. In other words, three years after the declaration of the epidemic by the Brazilian State and the WHO. Such municipalities are marked by a geography of precariousness (Peiter et al., 2020).
We sought to synthesize the main ideas, categories specific to the groups, in dialogue with the theoretical framework of State Anthropology, recognizing that the tensions in this field are updated in the expressions of the participants, to locate points of view with which they construct their arguments. In this course of arguments and speeches – recorded, transcribed, authorized by signatures of the informed consent form and with ethical approval, the following questions were raised: how microcephaly and the manifestations of the Zika-V epidemic are expressed by northeastern women and men related to it, due to the position of fathers and mothers or health professionals? When this social process is interpreted, what lenses appear to explain disease, health and prevention? How are the State and its agents, including health professionals, but also justice, security, documents, benefits, expressed and express themselves? What understanding of justice is constructed in this collection?

The discussion that follows proposes to weave dialogued syntheses between emic categories, recurring or elucidative expressions, which, interpreted by the researchers, will gain critical reflexivity using the previously posed questions.

The craftsmanship carried out with the collections, in qualitative immersion, does not seek to evaluate, judge or hold agents responsible, personalizing voices or positions. By organizing the perspectives of family members and professionals into separate sections, we highlight distinct, although sometimes convergent, points of view in the search for answers vis-à-vis the State.

This research refers to the study “Promoção da saúde no contexto da epidemia de zika: atores e cenários nos processos decisórios” [Health promotion in the context of the Zika epidemic: actors and scenarios in decision-making processes], financed by the Zikalliance Consortium (CEP/ENSP n. 67311617.8.0000.5240).

“Since it is a right, it has to come here too”: the law, the State, its agents and its games from the perspective of families

The “experiences of marginalization” (Williams, 1998, p. 15) are central for groups/people in the dialogue with their marks of belonging in terms of social inequalities. By critically reflecting on them, we reach references, peers, and collectivized places, which support their “perspectives” (Young, 2000, p. 137) in their view and voice on the world.

In Feira de Santana, four mothers participated, and in Natal, three mothers and two fathers. In Feira de Santana, one of the mothers indicates that her daughter
died, and would have been two years old at the time of the group, in 2018. This is the age of the children presented by the other three mothers with living sons/daughters. Criticism of the State, in complaints, accusations of what is “missing” and “makes the head worse” seeks a specialist and is unable to do so. The term “quality of life” is used.

The group opens up in critical elaborations on the SUS, which is “missing” for children with micro “neuro, a dedicated hospital, or a clinic focused on occupational therapy, ecotherapy”. An interesting dialogue between what the State fails to offer and the counterpoint “benefit x private pay x the amount does not cover”. The idea that “private is absurdly expensive. And then an example, the benefit that children have is not enough”. The notion that the benefit belongs to children, but cannot serve their treatments, places the State back in the role of guaranteeing rights. In Feira de Santana: “occupational therapy, a month is 480 reais”; “you receive a minimum wage benefit [to buy] medicine; in the Unified Health System, you don't always find it in pharmacies [...]”; “[buying] thickener, because it’s difficult to swallow [...] for you to get it through the public network, it’s more bureaucracy, send it to one person, give it to another”; “the benefit we have is not enough to meet the needs we have”. In Natal: “because those who have the benefit cannot work, neither the mother nor the father, so how are we going to survive with just a salary at home to buy medicine for the child? [...]”.

In the search for networks to access rights, in conversation with other mothers, it is reported that you cannot get “free diapers” in Feira de Santana, but in Salvador you can: “So, since it is a right, you have to come here too”. Children born with SCZV are in the category of children with chronic, rare and complex health conditions, also referred to as children with special health needs, children with technological dependencies, or even disabilities (Moreira et al., 2022). Recovering this clinical location refers to health needs and barriers to accessing the countless essential specialists for neuropsychomotor stimulation, absent in the nearby network and when found, they are dispersed, with numerous burdens for travel (Pinto et al., 2021).

In Feira de Santana, the pilgrimage for specialized care was emphatically highlighted. The dispersion of these treatments in different places – public, private, philanthropic, such as APAE, universities – is recurrent. And at that time, it was still in the preschool phase, with no daycare centers registered. There is also an ability to empirically evaluate the quality of the service, which can “be small, a space that
is for adults and children in the same room. There are qualified professionals who do it, but they send more students to do it, who sometimes don’t even know how to hold the child properly.”

It is common to refer to mediators, who we classify as non-human actors – who become pillars of a structure of life and rights: the free pass card, the car, the van for treatment outside the home (TOH), the value of a minimum wage which refers to the Continuous Payment Benefit (CPB), medicines, food supplements, probes, wheelchairs, prosthetics, and orthoses. These configure networks with humans, activating performances of care, expectations of how to behave, claim, collective learning, which influences care scenes (Mol, 2008).

Another arrangement of networks of networks concerns solidarity care mechanisms, based on help (Guimarães; Vieira, 2020). Such arrangements operate in informal and proximity networks that are created, for example, living in a rural area in the interior, when traveling to Feira de Santana through “alternative” transport, which does not accept the pass, but the “owner transport” says that the mother and child should not be charged for the fare, “up to two people end up in a car [...] because it has a car seat”; “if you go by bus you have to wait up to six hours because the bus carries more people”; “I prefer to go on the bus than reschedule. I’ll wait right there”; “you have to stay there until the afternoon because you have to catch other people to be able to come”.

The search to justify the faults, failures and games of State agents – sometimes incorporated by some mothers – to justify the failures in the law stands out, reversing the game of those who are at the center of the scene due to the fragility that constitutes it “It’s so much that they are trying because they are expensive.” In this case, “trying” and “being expensive” build an argument that supports the structural flaw of a policy that has to operate, which is not a favor. This happens with the TOH, with reports of “specific cars for microcephaly, to pick us up at home, take them to Salvador, come back and bring us too”. We highlight that this metonymic operation of talking about “microcephaly” as if talking about the child is a current expression, equivalent to what occurs in depersonalization structures consistent with the operation of stigma, of taking the brand as central, differentiating the child (Moreira et al., 2022).

Microcephaly is used to name the child in its complete existence, women are reduced to “mothers”, “little mothers”. The nurse “put in the way, doesn’t let me forget myself”. The State and its agencies gain layers that seek to compensate for the
margins of macropolitics. This macropolitics is also a biopolitics that defines who matters and who should be forgotten. But in the nurse’s agency, the justification for the woman, mother of the child with microcephaly, to take care of herself is again to refer to a metonymic operation of taking the whole of the woman’s existence, for one of her countless possibilities of existing: “Look, don’t forget you. Because she needs you, so you have to be firm.” The argument is restricted to someone in a situation of dependence on it. Look, this is not “the” nurse, but this scene evokes powerful elements of the structure of patriarchy that genders care and increases gender inequalities, with touches of blaming.

On the other hand, replacing care as ethics and politics means recognizing dependence and interdependence as constitutive of the human. In a State that does not adopt care as a policy, “losing” the mother through illness or death means abandonment, and even death. Those left on the margins of the State are marked by an active policy of precariousness and vulnerability. In this chain “there are other children too, then you go to her, then when you see there are others, then a home comes, the husband comes, you end up living for the last time”, care is configured as the production and reaffirmation of oppressions, asymmetries and forgetfulness.

The empirical category of forgetfulness takes on the contours of forgetting oneself, but it also appears in the active figure of the State and its agents, in which “the mayor promised an annex of service for us. And to this day, neither a representative nor a mayor nor anyone, nor anything. He was forgotten.” In other words, the active production of the margins is the active production of oblivion. That is why Boltansky (2015) serves us as a critical and analytical contribution, according to which the State and its agents can both intentionally kill the black children, of black mothers, from the outskirts and the poor, but they can also let them die “through forgetfulness”. Hence, the associative movements of women, mothers and children with microcephaly, in Brazil, take on the shape of confronting violence and abandonment by the State.

The attribution of the emic category “guilt” is triggered in Natal, where the group opens by locating the lack of sanitation and its connection not only with the Zika epidemic, but with dengue and chikungunya. In this case, the other non-human actor appears to locate the “culprit”; the government or mosquito. “Do I blame the mosquito? Blame! But I also blame the government for doing this, you know? So I tell you with certainty, so as not to blame them and they go and say that
it is the mosquito’s fault, that the mosquito is born like that”; “Before, the smoke car passed by. Even the muriçoca died. If they did their part too, because they ask us to do our part, there would be a lot of mosquitoes”. Easily, when shifting to the mosquito, the blame is shifted to individual behaviors “of the boy who accumulates plastic bottles” in Feira de Santana.

In Natal, the abandonment of the State constitutes carelessness towards those who “live at the end, live near Maré. It is interesting to use the “unfair” category to qualify this relationship between right / access / guarantee effectiveness “We go through so much difficulty and we think it is unfair, we have to seek justice. And there are mothers who live in the countryside, there are many things they seek justice for. [...] You have to go to court to be able to get something that is written by law, it is very suffocating”. Strategies to address injustice may mean omitting information that prevents access to benefits. So a father/grandfather criticizes his daughter, the mother of a child with a disability, his granddaughter, for not omitting it because he “doesn’t have the right mentality”, and ends up revealing that the grandfather earned minimum wage and “that was a problem for three years without receiving anything.”

The previous excerpt talks about learning and performances on how to behave towards State agents to be able to access rights, and negotiate the guarantee of needs. Here the criterion of justice is not impersonal and generic ethics, but an ethics linked to necessity. And the guarantee can refer to judicialization practices. It is up to families to exercise their rights. Create strategies, justifications, activate emotional repertoires to guarantee access to a right that they qualify as deserving, which, here, means fulfilling criteria intrinsic to their needs, and not what the impersonality of the State and its agents.

“Your baby is a baby that has rights”: Law, the State, its agents and its games from the perspective of professionals

The professionals’ collection highlights the contrast between learning about Zika during the work process and the behavioral dilemmas related to the fragility of the available actions. If each and every diagnosis is an initial milestone for establishing treatment and response to illnesses, the Zika epidemic is configured as an imperfect diagnosis, either because the relationship between being tested and having the results does not materialize – especially in the popular classes – just as having the diagnosis
means being faced with the “elephant in the room” (Kameda et al., 2021). The diagnosis raises uncertainty, and termination of pregnancy is not possible within the legal options for pregnant women affected by Zika. The collection contains this field of guidance for women not to get pregnant:

[...] there were people who we advised not to get pregnant during that period [...] two years without being able to get pregnant because of the risk that was imminent [...] it is an arbovirus, the most glaring consequence, which is most worrying is the issue of the syndrome itself, when it affects pregnant women.

The mosquito and the Zika epidemic are not democratic, they are related to environments where the proliferation of cases is linked to the neglect of the State.

In the collection, difficulties in implementing service responses to the needs of affected children and their families were evident. Feelings of great ambivalence were common: resignation with the situation, and/or personal engagement/surrender. The personal and professional spheres overlapped, and not infrequently, religiosity was used as a guide for actions and responses to afflictions. Professionals, given this emotional overlap, sometimes did not see themselves as agents of this State that does not recognize afflictions.

The image of the mother who fights against the State – which does not seem to be embodied in the actions of professionals who also see it as distant – appears in the fight in court for a medicine that “she could not buy due to the law that does not allow it. And she managed to receive all this treatment through the courts, she is the only one in Feira, at least, with microcephaly. Because she really fights, she is very active in justice and got the right to full treatment for the child.” In this movement, “the fight” connects justice/injustice, legal/illegal, in the face of an “insensitive” State.

It is interesting that the Brazilian State, through the Health Surveillance Secretariat, recognizes that:

After these years, there are still challenges to be faced: [...] expansion of monitoring of children’s growth and development, with the aim of qualifying the assistance network to better take care of identified needs and monitoring of research in development, seeking actions and preventive treatment and recovery policies, in an intersectoral manner in conjunction, especially with social security policies. Therefore, this is still an open agenda in the Brazilian health system and must be prioritized until we are able to qualify public policies to meet the different access needs in the SUS (SVS, 2020, p. 1-2).

In other words, we have a diagnosis of problems, and yet it is worth asking what prevents the diagnosis of problems from being configured into effective actions? Or

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even, how are problems expressed and faced between the State, its agents and the people who suffer?

This tension between the State and its agents is present. The idea that the role of local agents, of professional skills, comes up against a State that fails in its duties is a present keynote:

The objective of surveillance [is] to cut the chain of evolution and transmission of the disease. And then you try to cut the chain of transmission of the disease, but it is already there. And then you hear these reports from people who are there. So what are you doing, this may not be my responsibility as far as surveillance, but what are the authorities doing to stop this disease?

This question places responsibility outside the community, beyond the scope of the health surveillance professional, and speaks to the absence of links that connect State authorities and their commitments to basic sanitation. In other words, it refers to “who is above”, in municipal management.

There is, on the other hand, a tendency to hold the population responsible for their ills:

People accumulate rubbish at home, in the back of houses, you know? [...] does not depend solely on the goodwill of the manager. But there is also the part of educating the population [...] the social determinants of health in this regard are fundamental for us to understand this relationship between the number of cases, notifications and the issue of precariousness, the characteristics of the community [...] people gather rubbish, even rubbish [...] families that recycle and collect paper, PET bottles, which collect recyclable materials. So they accumulate a lot of materials and this is an aggravating factor.

In a set of ideas in which contradiction is present, we can think of a construct of searching for justifications, in which residents are responsible for “accumulating trash”, but they accumulate “trash” because they are collectors and make a living from recycling. It is worth asking how the State and its agents can organize recycling plants, organize associations around these practices and contribute to sanitation, and not interrupt a legitimate occupation.

In the emotional sphere, the mobilization dialogues with a “heroification” of mothers of children with microcephaly for their commitment to caring for their children. This process contributes to a lack of reflections or references to reproductive rights and/or termination of pregnancy as an option/alternative for mothers who discover the malformations of the fetus infected by Zika-V in the first months of pregnancy. This absence deserves a careful look, especially when it is common to
recognize the scenario of uncertainty about the effects of zika and the future of those affected, as well as the absence of a vaccine.

There is concern about how the State will take care of these children and their needs, not only regarding complex health actions, but social security.

The lack of knowledge of what was new, of being able to alleviate these difficulties and the pain of these families. The professionals created, from the network, from the municipality, this Aconchego project: the surveillance team was mentor, the entire network secretariat embraced [...] the objective of alleviating the pain and socializing the common problems of those families and the Aconchego project was created, which we gave this name due to the fact that we made this Aconchego, this name for those mothers, in this space we dealt with the issue of empowering that family, we brought professionals like the INSS to inform, guide about these rights, social workers. The Public Ministry was present, representing [...].

The agents of this “absent” State are configured in an action whose starting point is the lack of knowledge and the confrontation of suffering, and the so-called “empowerment through an exchange”. This action does not only operate at the level of mothers and their possible suffering, but also forms an articulation between agents, producing a network that was not on paper, in the promulgation of a law.

In Natal, the perception of the territories in which it operates is that of a general situation of need, with a lack of basic sanitation, which makes the environment more conducive to the proliferation of vectors such as Aedes aegypti. Added to this is the low-income level of assisted families with an average of one to two minimum wages and employed in informal and precarious services.

In Feira de Santana, the main health problems reported are chronic non-communicable diseases (NCDs) and situations related to living with disabilities, in which children with microcephaly are included. The care network is considered insufficient, generating dependence on highly complex care in the capital Salvador. The TOH is limited, generating insufficiency in more delicate care – due to convulsive crises, instability in cases of children with microcephaly, and restricted car and bus schedules “using the service daily, we have around 150 patients [...] and we have two large buses, a minibus, two ambulances, two small cars and a specific car for microcephaly”.

Traveling to distant services is qualified as critical, and leads to reflection that [...] if we had offered this service here, it would be much easier [...] And with children who have the syndrome, this happens a lot. The people who follow up, based on the address they provide, the professionals often go and [the addresses] don’t match. No, you live in
that municipality, you only come for consultation [...] Then in the end you end up discovering that it’s your uncle’s house, that it’s your relative’s house, your friend’s house and you won’t be able to deny assistance because of that.

Families learn and cultivate performance fueled by the healthcare system itself. The absence of a Birth Center in many municipalities in the interior forces women to travel to larger municipalities to have their babies, and on this route it is not uncommon for them to use the addresses of relatives residing in these municipalities to obtain access.

This perspective of complex needs generated by Zika-V in the lives of children and families brings together the idea that:

The biggest challenge that the municipality is seeking is to create a care center, a specialized outpatient clinic to care for children with the syndrome associated with zika. So there would be a pediatrician, nursing, physiotherapy, exams, infectious diseases. In short, it would have everything in one environment. Because a difficulty faced by these families is traveling to various services, both the question of time, the question of logistics, the question of finance.

The perspective of different times of care and recognition appear as similarities in the location of a State whose benefit allocation agencies, such as CPB, are not agile:

[...] barriers to overcome by mothers seeking help. The health sector works as a mediator of this flow [...] there is more information regarding this right specifically for children with microcephaly. So there was even greater dissemination, saying: “Oh, there’s a priority”. And the issue today is that when you go to make an INSS appointment [...] you only make the appointment on-line or over the phone, which is really unfeasible over the phone. [...] expertise is a quick matter to get the benefit. Our difficulty today is scheduling, to start the service. There is still no question of saying this, these are people who will have priority for scheduling. INSS does not do it.

In other words, health seeks to distinguish, recognize, streamline, and the INSS keeps the impersonal flow operating.

This situation leads us to concern about inclusion trajectories and access for these children to daycare centers and schools, which would allow them to continue their lives. However, the scenario of uncertainty makes it impossible to predict how the child’s development will occur:

[...] consequences that they can, in addition to these, leave for the future generation [...] we were not prepared, we did not know the disease, but now we know more or less what it causes, we have to alleviate the suffering for these families, for these children, try to prolong and provide a quality of life for these people, but what are we as social beings and what is our responsibility for this generation that will come. So what’s the point of spending so many studies, so much research if I’m not getting any feedback.
These images of the future, projects of quality of life to be offered, become unknowns, which the research called “studies” seem not to contemplate and answer. These pushing games, through processes of depersonalization of situations, contribute to a naming of the various agents involved, but it is in the family that the consequences are felt:

[...] this bureaucratic issue immobilizes you, you schedule it for 3, 4 months from now. Until then, the mother has to leave her job, sometimes the father left home, she was left alone depending on the help of others to survive, uncertain whether or not she will get the benefit [...] The municipality's Public Prosecutor's Office accompanies him, he wants to know if all the families that are in a situation of microcephaly here have been able to access benefits quickly.

The degree of suffering involved and exhaustion generate an overload in care, and women are most affected by this successive process of carelessness:

I think that in the first cases of microcephaly, the difficulty was that even the parents wanted to register, the men, in this case. Then the question of accompanying, of helping, of taking responsibility, because if you look at the mother, she gives up in the sense of work, of conception of her own life to take care of the baby to the detriment of, as everyone said, it's new, it's difficult and scary.

This location of care in the effects of gendering, asymmetry and oppression, leads us to think about where pushing games can distribute their careless effects, in the demands of State agents – Public Prosecutor's Office, for example – and to what extent it is on the most vulnerable families. precarious situations that affect judgments and moralities, and less support.

Final considerations

If we open by remembering six or seven years ago, it is important to remember the possibility of a new Zika epidemic, without having stopped having babies born with SCZV today nor recovering from the Covid-19 pandemic ongoing with almost 700,000 death records in Brazil.

The succession of health crises since the turn of the century, in addition to the suffering caused by the loss of human life and family dramas, helps to fuel the processes of producing social inequality, precisely penalizing those who would most need support from the State. These crises occur in a context of decreased capacity for State intervention, deliberately planned and calculated by the imposition of the neoliberal agenda. In states like Brazil, historically besieged
by private interests and marked by an imbalance of forces and injustices, this situation is even more acute, raising the need for a permanent and unrelenting struggle for the establishment of social justice.

In this sense, the suffering of mothers and families in the context of the Zika-V epidemic must be interpreted not as something individualized or subjective, but brings to light the idea of social suffering, or as Ceres Victora reminds us (2011, p. 3, free translation):

[...] of suffering intrinsically linked to what I like to refer to simply as the policies and economies of life, verified in specific historical and social conditions and configurations. It is in this sense that it becomes essential to observe how political, economic and institutional powers are intertwined in personal and everyday experience and how people react to events on a daily basis.

The idea of pushing games prevails as a metaphor for various movements of disempowerment, disinvestment, insufficient responses to necessary care and generating overload and suffering for women, when it comes to caring for their children with disabilities. Pushing games are then configured as another factor of care not instituted as Politics. Children affected by Zika-V join the ranks of children with disabilities and complex health needs. The consequences of pushing games compromise the rights plan and demarcate a trajectory of lives in which fighting is not a choice, but a necessity.

Even professionals occupying the role of agents of the State, often do not recognize themselves as such. And they experience a lot of closeness with the population for which they provide care. The Zika epidemic was a great social mobilizer, which affected families and professionals who knew little, but who, as agents of the State and knowledge, were called upon to respond. With these considerations, future research should understand health emergencies from a place of mobilized or restricted solidarity.¹

References


PINTO, M. _et al_. Cuidado complexo, custo elevado e perda de renda: o que não é raro para as famílias de crianças e adolescentes com condições de saúde raras. _Cad Saúde Pública_, v. 35, p. e00180218, 2019.


Note

Resumo

Manda pra um, joga pra outro: a emergência sanitária da zika nas margens do Estado

Distantes temporalmente da declaração da emergência em saúde pública de importância internacional (ESPII) e emergência em saúde pública de importância nacional (ESPIN) provocada pela epidemia de zika, no ano de 2015, enunciamos a herança da emergência humanitária. Com base em uma pesquisa qualitativa, por meio de grupos focais realizados com profissionais de saúde e familiares das crianças afetadas epidemia de zika em Natal e Feira de Santana, buscamos discutir esse fenômeno de saúde pública pelas lentes da Antropologia do Estado. Concluímos que o não reconhecimento do Estado como uma instância encarnada no cotidiano das práticas por parte dos seus agentes locais leva à reprodução de práticas discriminatórias esvaziadas de sentido político e do reconhecimento de moralidades que permeiam as ausências nas ações de promoção de saúde e estratégias de reconhecimento e busca por estratégias para a garantia do direito à saúde.