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dossier

Zika virus: an epidemic in/and its social world

Zika, women's prominent role and care: rehearsing contact zones

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In this essay, we dialogue with themes launched in the post-epidemic debate of Zika Vírus (ZIKAV), on the lives of women and children. We analyzed 23 Brazilian papers published between 2016 and 2017, selected in Brazilian journals, in the fields of Social and Human Sciences. There is a mixed speech of claiming for rights - grand narratives of social appeal and explanation by the social forces of a negligent State – associated with minor narratives of caring for a disabled child. We tentatively conclude that the contact zone is the movement of retrieval of the minor narratives in the translation of the iniquities produced by the State in the life of ordinary people.

Keywords: Disability. Women. Children. Care. Zika.

Introduction

We have been living in the post-epidemic period of the Zika Virus (ZIKAV) since November 2015, followed by the Ministry of Health (MS) and the World Health Organization (WHO) health emergency declaration in 2016.

If viruses and mosquitoes gained status as players – portrayed in human dimensions – people, particularly women who became pregnant, lived with unanswered issues. A body in pregnancy with marks named as allergy, virus disease and "nothing to worry" was part of the scene¹. A feeling of malaise – without convincing diagnosis or response – was being built in imaging tests as from pregnancy, translated into inquiries about fetal development. Abnormality would mark these children from the womb and then birth, with below-standard head





circumference measurements, microcalcifications, endless sobs of inconsolable babies with shocks labeled as "scares". When disability or abnormality affects children, the image of the self-sacrificing mother, often portrayed in a state of paternal abandonment, emerges in a setting of misery, denial of rights and excessive vulnerability.

If the mosquito is democratic as some have claimed, why were portrayals in the press of miserable, exhausted and choiceless mothers? The narratives of disability appear here *pari passu*: fathers who abandon disabled children and women; women of the most privileged classes who are not the target of headlines; the impossibility of talking about the rights of women to choose or not to have a disabled child according to social class, ethnicity / color and generation markers and the lack of prominence on sexual transmission of ZIKAV.

According to Santos², it is necessary to realize a sociology of absence, transforming impossible objects into possible ones, and building on them, turn absence into presence. His analysis is not external to science, criticizing metonymic rationale that produces power dichotomies, subjugating one sphere to the other to produce a new totality, erasing parts, imposing homogeneity from a single order of reference, whether of scientific knowledge, masculine and racist order or of normality patterns.

This essay emerges as an analysis of part of the knowledge production of social and human sciences in health within the post-epidemic framework of ZIKAV, which has already been recognized in editorials of journals³⁻⁵. It evidences children disabilities, interdependence among actors-state, scientists, vectors, media, civil associations, women's movements that do not necessarily converge to the agenda with feminist movements, care and gender-related division of labor – and whose reflective power over neglected populations must be addressed.

The ZIKAV epidemic produces experiences on social inequalities in access to rights and unveils an impressionist setting: pregnant women affected by the virus, causing the birth of children with unexpected health needs, marked bodies and tests that reveal a non-standard neurological system even for microcephaly types already known as a result of other congenital diseases. Stories of poor Northeastern women stand out, who organize themselves to demand from the Brazilian State to show their responsibility towards the epidemic and its consequences on the lives of their children.

We triggered a theoretical analysis for a certain sociology of emergency and absence in the post-epidemic context of ZIKAV, resorting to what has already been written in Brazil on the subject, from the perspective of social sciences and humanities.

In contrast to monocultures, Santos^{2,6,7} builds a dialogue with the rationale of five ecologies: knowledge, temporality, recognition, trans-scales and productivity. In a dialogue with narratives of intellectuals about ZIKAV epidemic and its human interfaces, we opted for the ecology of knowledge for this essay. The author argues that the sociology of emergency and absence is coordinated through translation, identifying counter-hegemonic movements in each

moment and concrete historical context. It is simultaneously an intellectual, political and emotional work revealed in the realization of non-fulfillment of even conventional social sciences³.

Highlighting the post-epidemic moment of ZIKAV, we reflected on mothers' movement in coexistence with feminist and women's movements. The sociology of emergency is coordinated with the realm of care; it means recognizing it from the specificity of the objects studied, from the place of speech⁸ of its agents. If the care we are talking about concerns children born with signs of chronic and complex disabilities and health conditions⁹, we must include women who care for them. One of the challenging dichotomies is the absence or obliteration of children as opposed to adults. Children marked by structural dependence on adults have not been able to pull themselves out of adult-centered view¹⁰. In order to understand the child as a transforming subject of culture and social relationships, social studies of childhood allied to child anthropology revive the idea of children's leading role, questioning the concept of socialization that subordinates children to institutions, triggering the perspective of sociability produced by children as being active in their encounter with institutions.

The importance of locating who is mentioned, how one speaks and how this subject appears or is erased in the public arena is now urgent in this context in which almost 3,000 children born under the aegis of ZIKAV are also part of the number of children living with disabilities and complex chronic health conditions suffering with the absence of the state. This paper intends to portray an interim transitional exercise of the present, expanded by sociologies of emergency and absence, shedding light on themes thrown in the post-epidemic debate of ZIKAV in the lives of women and children, seeking contact areas between grand and minor narratives produced by intellectuals and activists from the field of social and human sciences.

Proposed methods

We refined our writing as an essay, in the light of Larrosa¹¹, staring at the now, where authorship, criticism and writing result in a movement of experimentation. The 23 papers analyzed were published in the period 2016-2017, considering that news about ZIKAV came to us in 2015. We chose Brazilian journals, focusing on the field of social and human sciences in health, noting that part of these papers composed dossiers of journals, conducted by organic intellectuals of this field. Descriptors were not the search criteria, but a certain cartography, where the ZIKAV epidemic was highlighted, and from reflective, investigative writings, sometimes also of essayistic nature, announcing absence and presence. With this intentionality, the collection was sufficient for such exploration of movements, stakeholders, interests and reflections that fostered the essay.

Considering we are immersed in minor and grand narratives¹², we turn to these axes when we look at this intellectual production. The grand narratives are not confined to ideas about progress, development and modernization, but stir discussions on global health, reproductive rights

and social media discourses. Minor narratives value analyses aimed at the care of children with microcephaly and stunted neurodevelopment and the organization of their mothers voicing their rights.

We considered: (a) in grand narratives, the field of global health, national policies and social determinants, debates on reproductive rights and analyses of media discourse; (b) in minor narratives, post-epidemic child care and support coordination among mothers of children marked by ZIKAV.

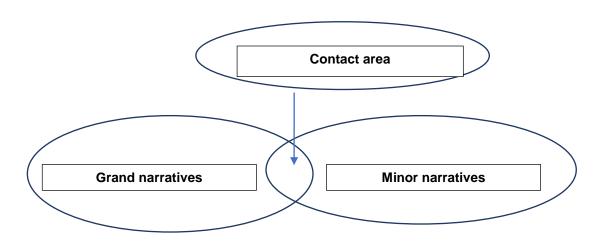
Table 1. Organization of the collection of papers

Papers organized according to Narrative Axes		
Grand narratives		Minor narratives
	Rego and Palacios ¹³	Scott et al ³⁰
Group 1	Nunes and Pimenta ¹⁴	Fleischer ³¹
Global Health	Ventura ¹⁵	Pinheiro and Longhi ³²
	Lesser and Kriton ¹⁶	Diniz and Brito ³³
Group 2	Antunes et al ¹⁷	Lara Netto ³⁴
Media	Aguiar and Araujo ¹⁸	Galli ³⁵
	Porto and Moura ¹⁹	
Group 3	Baum et al. ²⁰	
Reproductive	Galli e Deslandes ²¹	
rights	Neves et al. ²²	
	Carvalho ²³	
	Diniz ²⁴	
	Pitanguy ²⁵	
	González-Vélez ²⁶	
	Luna ²⁷	
	Camargo ²⁸	
	Stern ²⁹	

Science builds narratives producing knowledge and responses to society. As Latour would put it 36,37 , this pathway between the question asked, the methods used and results achieved

hegemonically appears as a black box. When we focus our criteria on papers of social and human sciences in health, we seek to find narratives that unlock this box, whose methods explore critically the common discourse, the media and official documents, revealing the hidden, which is constructed in public speech intervals. Initially, we organized papers with this differentiation between 'grand' and 'minor' narratives to achieve the proposal of Charles Tilly, retrieved by Stanley³⁸ and Castellanos¹², whose narrative analysis favors interconnections, articulated thinking between the universe of social structures and people's realms.

We identified the contact areas² through the translation exercise, in dialogue with disability, with women movements and social and health policies. We interpreted papers in this dialogue between narratives, focusing on emergency and absence, emphasizing that the analyzed collection adopts an anti-hegemonic stance vis-à-vis traditional science.



Arrangement 1. Analytical coordination of the theoretical proposal

The question asked to the collection in this essay is "Are minor narratives updating grand narratives, in the contact area generated by the ZIKAV epidemic, from the interface between gender and disability?" Under the assumption, the essay understands that the ZIKAV epidemic reverberates in the public arena and calls on the state to see these children through the lenses of research that will be not be limited to just biomedicine nor hospitals, but will visit homes, associations, newspapers and websites. These places and because of a national and international epidemic/emergency context, bring to the forefront the lack of a network for the care of people with disabilities, especially children, revealing health inequalities.

The contact areas between grand and minor narratives

Grand narratives conjure up global health and restrictions on female reproductive citizenship³⁹. The visibility of inequalities that permeate them is highlighted in the saying "Mosquitos are democratic" ¹⁶, which has been spread by the media in dengue epidemics. It is not the neglected diseases, but rather people, their social determinants and markers of difference, especially class, skin color / ethnicity, generation and gender.

In a semantic chain, papers portray dichotomies of the so-called metonymic rationale²: global and local tensions between community and individual fields. Starting from questions about why an already known virus would trigger so many unexpected diseases, the structural issues of the health-disease process, known by the Brazilian State in the proposed war against exogenous agents such as Aedes aegypti and in the case of ZIKAV by the global threat setting made by the WHO through the activation of the "legal-political figure" of Public Health Emergency of International Importance gain prominence.

Criticizing the apolitical perspective of global governance (neutrality) and the belief in technical solutions (scientificity), the discourse of securitization at the expense of questioning the experience of illness and living¹⁵ emerges. Recent experiences with Ebola and the history of HIV/AIDS show the risks of this process, such as the spread of fear and stigmatization¹⁴. A semantic chain on ZIKAV, in a continuum of denominations, is expressed in the policies of Aedes; war on the mosquito; health emergency; global public health problem; microcephaly outbreak; Zikaphobia, Zika Virus Congenital Syndrome (ZVCS): an "epidemic of meanings" 14,40,41.

In a process marked by gender inequality, conceptualization and normalization can be perceived as a need to justify decisions and proposed measures in the face of the unexpected intergenerational unfolding of ZIKAV exposure during pregnancy. Research on this association and fetal neurological impairments were under way in 2016 and papers from this first bloc express ethical concerns in care practices provided or neglected to those exposed and relationships among different stakeholders in the field of research. Tensions between individual freedom and the role and duty of the state are highlighted by considering the limits of women's reproductive rights and demand for a childcare network and support to children's families¹³.

Papers that focus on the ZIKAV epidemic in the media underscore a public discourse that reaffirms gender asymmetries, institutional violence on the bodies of women, who appear sometimes as victims and sometimes as culprits, in both positions, unable to decide¹⁹. Social stakeholders of religious representativeness against the decriminalization of abortion appeal for the respect for fetus life. Facing this news as social constructs, papers articulate the ideological component in the narratives of experts and those who are directly affected by the epidemic and its consequences: women and their families and health professionals. Stances of the Ministry of Health as a privileged stakeholder in opinion making elicit pictures of infants with microcephaly as a "lost

generation" and virtual social networks evidence poor women exposed to state violence. On the other hand, the Pan American Health Organization points to the clinical *feeling* in the experience of Pernambuco on the association between fetal defects and ZIKAV in pregnancy, in a double subversion of hegemonic dichotomies between professional caregivers and academics/experts, as well as in the geography of knowledge production in the Northeastern and Southeastern hubs.

This epidemic makes science rediscover women by producing science, knowledge from the bedside and the poorer Brazilian regions¹. The media outlines a temporality about affected babies, envisioning them in the future as children, highlighting the maternal figure associated with care and the recurring image of men abandoning their families. Perhaps the novelty is in the interactions between siblings, and thus the participation of other children in the care, and NGOs established by mothers of children with microcephaly caused by different pathologies.

We emphasize Aguiar and Araujo¹⁸ and Antunes et al¹⁷ who worked with pictures published in print newspapers and Instagram, respectively. Evidencing the words fear and risk, coupled with a high degree of uncertainty, they highlight a gap in the care for the epidemic that explodes in the North-Northeast axis, and later in the South-Southeast region¹⁸. There is no lack of reflection on the memories of the HIV epidemic and the discursive records that silence a so-called risk group marked by discrimination¹⁷. This classification serves the neoliberal argument that works with restrictive agendas. Historically, social movements of people living with HIV/AIDS have had a strategic role of holding the State accountable. In the case of ZIKAV, pictures of pain, suffering and malformation of infants had few previous public references, with the predominant discourse of prevention and risk, individual responsibility, with less emphasis on the political correlations of the epidemic.

The narrative about disabled children is confused with those with microcephaly, limiting them to their marks. The State's responsibility relationship in not assuring an effective network of care and rights for people with disabilities penalizes women twice, by poor attendance of failing public policies and by failing to recognize their reproductive rights. The less enlightened, yet named references refer to the abandonment of children with microcephaly in shelters, associated with poverty and loneliness of these young women.

The third set of papers shows the production of researchers and feminists, especially Brazilian women, about reproductive autonomy, reproductive planning and legalization of abortion in the context of ZIKAV, pointing out women's constraints in exercising autonomy over their bodies, lives and reproductive choices. From the ZIKAV phenomenon, they analyze the historical moment, its complexities, highlighting advances and setbacks in the debate on reproduction and women's rights.²³ This production is a "reaction" to the first measures taken by the Brazilian State in the National Public Health Emergency declaration, in November 2015, in anticipation of WHO.

Addressing the reproductive autonomy and abortion – issues dear to the feminist agenda – they denounce their absence from the ZIKAV²⁰ epidemic coping agenda. While it is a signatory of international conventions and agreements related to women's rights, Brazil relives a conservative

legislative environment, where rights gained are threatened. The difficult advancement of reproductive rights is an important agenda, signaling an arena of disputes and tensions²⁵: silence regarding abortion, problems of access to information and inputs related to reproductive planning and possible setbacks in the field of reproductive rights^{21,22}. We highlight the fact that the ZIKAV epidemic has affected the poorest women, mostly black and white, with low schooling and living in the most impoverished regions of the country. Ethnography-inspired works²⁴ with an intersectional perspective²⁹ point out that, in families with children born with the ZIKAV marks, the heaviest burden falls on the shoulders of these women. The asymmetric distribution of care work places them in the position of primary responsible for the health conditions of these children, requiring an intense routine of specialized treatments.

The State's duty to ensure access to health care becomes crucial and its constraints evidence inequalities²⁴. Works point to the need for a dialogue between groups that discuss the issue of women's right to choose abortion and groups advocating the rights of the disabled, rebutting the issue of eugenics^{28,42}. Dialogue between international and global discourses, especially with the WHO, and the Colombian case of the effective access to abortion in cases of ZIKAV by women with mental health impairment and demand it revives the argument of the right to abortion²⁶

The minor narratives favor the statement of children's bodies, not allowing their mothers to forget their needs, transformed into public discourses of struggle for rights, justice and reparation: first-person narratives, in which northeastern women, mothers and health professionals play different leading roles in the epidemic, but in multiple linkages³³⁻³⁵.

Emotion is a connecting fabric, as is the production of mothers' knowledge about their children, who are relegated to oblivion in the face of other life experiences with unmarked children. Professionals live with surprise and suffering reading the altered imaging tests. In addition, children development's landmarks become grey areas, due to the unknown action of ZIKAV in the body. Bearing in mind differences, Vianna and Farias⁴³ locate the condition of mother as element of moral authority in political acts. They enable a shift "between personal pain and collective causes; between sufferings and rights; between different forms and realms of mourning" (p.83). This moral authority triggers a triad that relates mother condition / political stakeholder / action that dialogues with the victim's status of the dead son, and allows the simultaneous conjugation of a narrative of the "I" and the "we". The mothers of children born with ZVCS are fighting for justice and ascribe to the State the responsibility for their pain, the mourning of a child without abnormalities, whose deficiencies they bear witness.

The accountability of the Brazilian State conducts this narrative in its origin, revealing its flaws, now offering rehabilitation and schooling actions for children, prompt social benefits and recognition that they need to be protected from intolerance. If this narrative is built in contact with one of the leading mothers³², it is not personal, but acquires hues of the political representation of the "statement of many" – translated in a mother's discourse through text messaging applications

and Facebook pages – connecting the grand narrative of state accountability, the limits of policies and rituals of social discrimination.

In the interaction with the media, fathers' presence is currently recoiled so that – even if some fathers are indeed caregivers – mothers are prominently portrayed with their children. The mother-child dyad predominates in the public picture, reaffirming models of parenthood in which women are identified as single caregivers. Having a child born outside normal expectations is a time of "seclusion", where this child is censored, hidden and the family can be the locus of prejudice³². The figure of maternal self-denial conflicts with the feminist stance; it emphasizes militant motherhood, the preponderant role of mothers who fight for children marked by disabilities, erasing the woman-wife trait. Children assume the identity of angels and issues about reproductive rights and perspective of care with future pregnancies lose space.

As propulsive springs, these identity realms – of biological citizenship and biossociability – coordinated and coordinators of social support generate an associative movement of mothers of children with microcephaly by recognizing their children as disabled and thus accessing the rights associated to this condition that assures them the status of citizens^{44,45}. It is interesting to identify references to contrasts and tensions with mothers of other children born with rare diseases^{30,32}. If they initially draw closer, then they differ: what the rare ones cannot and still struggle to achieve, mothers of children with microcephaly expedite in public debate – in dialogue with the Executive, Judiciary and Legislative branches – gaining visibility by direct association with location of the agents responsible for the advent of malformations and diseases: the mosquito and the State. There are several performers in the interactions promoting these maternity reconstructions and identities. They are well attuned to the analysis of stakeholder-network theory^{32,36,37}.

Institutions, blood, researchers, tape measure, car, diapers, mothers, parents, children, ID card, provision benefit, WhatsApp, virus and mosquito. If the media provided ephemerality, these papers represent a "not forgetting", conjuring up presence and daily life. First-person reports emphasize proximity, alterity and reciprocity in the movements of holding, walking and speaking³¹.

These are expressions of the temporality of life experience and the gradual expansion of the intersubjective encounter between the mother, her baby, other mothers, the researchers, the State and social discrimination processes, a gradual recognition of this child as her own, preceded by her own prejudice to introduce him to public life, recognizing his needs, interpreting him and gaining intimacy with him, defending him, transforming him into an angel, a symbol of the organized struggle of mothers of the first generation of children born with microcephaly associated with ZIKAV. This group of papers evidence the urgency of translating experiences as researchers in the encounter with mothers who seek to elicit the needs of their children with disabilities. This collection contains identifications and distinctions between being a rare mother and being a mother of an angel³⁰. The militant woman-mother-of-an-angel-child highlights the collective dimension of inequality in health marked in the generation of mothers of microcephalic children, which is not in the rare mothers, whose organization is determined by genetic inheritance and not by the impasses

of a viral epidemic transmitted by an external agent. At the base are disabilities in children born after being affected by ZIKAV in pregnancy, and this scale event triggers an international and national health emergency with state accountability. It is not the place of a wife or the picture of a father that which is evoked, but rather of motherhood associated with the struggle for the child, whose disability mark stands out in the tensions³⁰.

The closing gap between feminist studies and childhood studies does not occur without conflicts and estrangement. On this subject, Helleiner⁴⁶ revives its history when talking about feminism and childhood: as an anthropologist, it was strange to recognize some interest for children, since she was a feminist. Taken by this apparent contradiction, from a certain antithesis between feminism and child, Helleiner allows us to expand our horizon and criticism of what Santos² labels as metonymic rationale, which is one that works with opposing pairs in order to move to locate the parts in the whole, reducing the complex nature of relationships and valuing only one sphere. Therefore, in order to talk about women, we would have to talk about men; to talk about children, we would have to trigger adults; to talk about reason, we would have to oppose emotion, and so forth. Santos² believes that "criticism of metonymic rationale is, therefore, a necessary condition to retrieve the lost experience. The expanded world through the expanded present is what is at stake." (p. 245).

If we were to perform the shift of adult-centered and developmental rationale that inhabits the universe of analyses about children and childhood, we would move from the axis that confines the child to a socializing project of adults, a project for the future that erases the value of the child in the present. Children with developmental stunting and microcephaly live the future as an announcement of a nebulous becoming, which in the Ministry of Health's discourse, labeled them as "lost generation" at the time. This narrative voices the metonymy of a future lost to the abnormality and disease of the biological model of disability⁴⁷. Reductionism generates symbolic and long-term effects, conjuring up the rituals of discrimination from the bodily stigmas that are visible and produce identity traits⁴⁸. Being a mother and being recognized for the care of a child with a disability supersedes any other identity mark, reactivating the debate about the distressing experience of disabilities in the interface with gender inequalities in care⁴⁹. We are summoned to a social reassessment^{5,37} exercise, which is discussed as a mixed philosophy⁵⁰, where opposing axes would be less dichotomous, more dialogical and tenser.

Tension does not equate to dichotomy, but incorporates a contrast, with contact areas that trigger movement and a sense of opposition. We experience these ZIKAV effects resorting to reticular, relational, symmetrical and reconnecting effects between humans and machines and subjects and objects. In Carneiro's proposed existential connections⁵, supported by the stakeholder-network theory^{36,37}, these mixtures would promote multiple movements, transform concepts, categories and ways of acting and conceiving the world. A mosquito, a pregnant woman, a virus and a child: where would boundaries start and end?

Conclusion

The grand narratives to explain a phenomenon in the interface between care and disability, mobilizing women and public opinion and experts and the media do not ignore the delicate movements of meeting with the unknown, the impotence of knowledge and the actions of coping with suffering and gender inequalities. In this setting, the feminist movement and other social movements, such as the black one, that of people with disabilities are approaching, but women who embrace this maternity identified with the biography of microcephaly and disability do not necessarily want to speak about these banners.

We identified grand and minor narratives while searching for absence and emergency. A mixed discourse occurs in these contact areas, characterized by polarities. We highlighted the relationship between microcephalic children and children with disabilities/special needs, further evidencing the former due to visual marks and because they are a synthesis of the epidemic in the emergence of a novelty: microcephaly associated with ZIKAV and a vector. However, minor narratives represented by mothers of these children claim they are special and angels.

Being special and angel ensures greater recognition in the field of common discourses, as well as in the field of public claim for identities and social benefits. Another announced absence, but which dialogues with former emergencies concerns spreading routes, where sexual transmission suffers an obliteration, which seems to rekindle the missing discussion over sexuality and reproductive rights, and should these be discussed, they will be tamed.

There is a mixed discourse of claiming for rights – of large scale, or grand narrative of social appeal and explanation by social forces regarding a State that is remiss – and, at the same time, a small narrative of the daily care of a child with disability that is localized or circumscribed to the struggle for legitimate interest in not being forgotten, ensuring health, rehabilitation, education and benefits. Associative interaction is built up in "crossbreeding" fashion: mothers of children with rare diseases, with the most varied diagnoses, gathered around this identity, of little incidence and almost invisible, and mothers of children born with microcephaly or ZVCS, who gain volume and visibility and differ through the epidemic. They expedite something the former took a long time to achieve: a recognized public place, the interest of researchers and policymakers and visibility for a group of children who generally go about unnoticed: those living with disabilities. Perhaps social emancipation comes to recognize the heterogeneous and hybrid character of women voicing the rights of their children born with the marks of microcephaly, of developmental alterations, renegotiating with several markers: ethnicity/skin color, gender and disability. Of these three markers of difference, perhaps disability conjures up others referred to the picture of angelical children, their rights, their non-choice and responsibility for this altered birth in their social heritage.

Collaborators

Martha Cristina Nunes Moreira has developed the theoretical and methodological conception, reviewed the text, discussed the results and approved the final version. Corina Helena Figueira Mendes and Marcos Nascimento have reviewed the text, discussed the results and approved the final version.

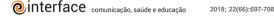
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