

Zika virus and women

Vírus Zika e mulheres

Virus Zika y mujeres

Debora Diniz^{1,2}

¹ Faculdade de Direito,
Universidade de Brasília,
Brasília, Brasil.

² Anis – Instituto de Bioética
Direitos Humanos e Gênero,
Brasília, Brasil.

Correspondence

D. Diniz

Anis – Instituto de Bioética
Direitos Humanos e Gênero,
C. P. 8011, Setor Sudoeste,
Brasília, DF 70673-970,
Brasil.

d.diniz@anis.org.br

Epidemiological surveillance describes numbers and cases. As of March 12, 2016 (Epidemiological Week 10), there were 6,480 suspected cases, 1,349 rejected cases, and 863 confirmed cases of microcephaly or other alterations suggesting congenital infection caused by the Zika virus in Brazil. In 97 cases, the presence of the mosquito-borne virus was confirmed by specific tests¹. Epidemiological terminology makes us forget that these cases were preceded by women who were affected by the Zika virus – discarding these women cannot be justified by the biopolitics of diseases. The Zika epidemic, which involves cases of microcephaly and/or other alterations in the central nervous system associated with viral infection², affects women from a specific social class and region: poor women from Northeast Brazil. Seventy-two per cent of the babies born with the symptoms of Zika virus congenital syndrome in Brazil are born to women who live in the northeast states of Bahia, Paraíba, Pernambuco, and Rio Grande do Norte. Simply referring to cases ignores the stories and the suffering, the anguish and the abandonment.

In December 2015, Pedro I Hospital in Campina Grande, Paraíba, Brazil, initiated a Microcephaly Clinic. In March 2016, two or three times a week, 40 women would bring their children from cities from the districts of Sertão, Alto Sertão, and Cariri for early infancy stimulation and consultations with pediatricians, psychologists, and ophthalmologists, as well as make trips

to the Brazilian Institute of Social Security (INSS) offices in order to be able to receive social benefits. They are very similar – young, rural farmers or unemployed, with low levels of education, and dependent on health services and public transportation in order to be able to care for their infants, who have multiple impairments caused by the Zika virus. When they were pregnant, they were not informed that there was an ongoing epidemic, and many of them describe the symptoms of Zika during pregnancy as “in my town, everything was a virus”³. They are daughters and granddaughters who have been dealing with the vector mosquito as part of their daily lives for more than four decades.

This was the first generation of pregnant women infected by the Zika virus in Brazil. Some of them were informed that their child had been affected by the virus during the ultrasound, at the same time that biomedical research was still drawing relational or causal hypotheses; they lived through moments in which they were neglected by both health assistance as well as science⁴. Microcephaly is an ambiguous metonym for the effects of the Zika virus in the fetus for at least two reasons: it is the most evident sign for diagnostic imaging or for head circumference measurement of the newborn in epidemiological surveillance records; however, for most of the women⁵, it is also the sign that “*the only problem with my child is a smaller head when compared to other children*”.

Just as we cannot ask science to provide precipitous answers to unknown phenomena, we cannot ask women to anticipate the effects of the neurological impairments by reading a rehabilitation manual: they will become aware of their children's individual needs while raising them. The age of the children varies between one and three months, a period in which infants are naturally dependent, thus making it reasonable to state that *"my child is normal; he only has the microcephaly problem"* ³. Women have been identifying the effects of the Zika virus on their children with the scientists: they have already adopted the biomedical language of microcephaly and calcifications, but not that of congenital syndrome; they attend the early stimulation sessions and are concerned about the baby's intermittent crying; and they learn that their babies have visual or hearing limitations during the pediatric consultations. On the other hand, they make up their own science of domestic observation – they describe the permanent signs of irritability (*"for every ten minutes of sleep, she cries for an hour"*), and give details of the feeding or mobility difficulties the babies have. The result of this negotiation between biomedical uncertainties and permanent observation through motherhood is the resignification of "special" to describe the unique traits of the children – they are referred to as special children.

A "special child" may be a term that has been shunned by the disability rights movements in urban, political, and academic centers, but it is a comforting expression for the rural women from the Northeast of Brazil, who are now dealing with an epidemic that has made their lives precarious ⁶. To have a special child is a divine ordeal for some of them, with motherhood as a required condition for survival. There is a life-giving relationality between mothers and children which makes it easy for their lives to become subjected to the increasing demands for care: trips in improvised transportation from rural cities to Campina Grande; ten-hour daily trips to attend thirty-minute early stimulation sessions; waiting for "help" to feed the child, since many newborns struggle to breastfeed. The inherent relationship between ethics and maternal responsibility is exacerbated by the precarious lives of the women, not only by the vulnerability of the newborn ⁷.

In the Pedro I Hospital waiting room, women recognize that they form a community of the epidemic; they compare the effects of Zika on their children and investigate differences concerning the time of intrauterine infection and the impairments in order to improve domestic science – they begin to explain to me how the infection at the beginning of the pregnancy caused more

damage in a certain child; one of them draws my attention to how her child has developed better as compared to another child who began early stimulation later. Their primary complaint is about access to cash transfers, described as "government aid", because basic needs are covered through "help from foreign journalists" or sporadic charity from health professionals, neighbors, and family members. Almost all of the 40 women have been interviewed by international news shows and agencies, which sometimes describe them as "Zika mothers". These women want to tell their stories, but as a consequence of being seen and listened to across borders, they expect to receive protection from abandonment.

One of the women lives on a farm three hours away from Campina Grande. She used to work in cotton farming before she gave birth, and separated from her partner after their baby was diagnosed with fetal microcephaly. She survives with the "help" of her family and neighbors, and describes herself as *"permanently troubled"* – she barely sleeps because of the child's crying, and her INSS medical intake report has not yet been scheduled. She was recently visited by a foreign journalist who asked to see her kitchen, *"he and the translator cried when they saw the empty fridge. Later, I received food that lasted more than a month"*. Her neighbors now ask her why she does not do more interviews, since that could guarantee her survival while *"the government does not see what happens here"*.

The truth is that they were already anonymous women before the epidemic. Poor and living in the Northeast, they survive a broad spectrum of regimes that make their lives precarious, with poverty the worst of them. The epidemic was a tragedy for unintelligible lives – the epidemiological surveillance numbers consider the children to be cases for notification or confirmation, yet they are silent about the women. These 40 women gave birth between August 2014 and February 2015 and are very poor, but none of them are protected by the federal government Cash Benefit Program (BPC in Portuguese) – the income limit to have access to the program, 1/4 of the per capita minimum wage, requires that they be even more impoverished or abandoned by their employed husbands in order to receive the benefit. Also, the bureaucracy associated with going to an INSS office is a huge barrier to women who are full-time caregivers; none of the few who managed to apply have even been called in for an evaluation. Bureaucratic time is not on the same timeline as the urgent needs of these women and their special children.

A second generation of pregnant women infected by the Zika virus is now coming to prenatal

clinics in Campina Grande. There is an important difference between them and the first generation – a year ago, the unfamiliarity with the circulation of the virus made women witness the discovery of the effects of the virus in their own bodies. The women from the second generation are aware of the virus since the information about the risk of the epidemic is available to the public, though uncertain: Pedro I Hospital sees children with the congenital syndrome from 22 cities in Paraíba. The second generation of these women are living through a more tormented experience: some women prefer not to undergo the prenatal routine if they present symptoms of Zika infection; some refuse to have ultrasounds, a tendency that has already been identified among other women⁸. They choose not to know because there is nothing they can do about it: without the right to terminate the pregnancy and with many scientific uncertainties, an early diagnosis is simply psychological torture. Since there is nothing to offer these women – in the words of one of the doctors in charge of the Microcephaly Referral Clinic, “*here we offer hug therapy*”, some pregnant women infected by Zika prefer to resign themselves to the abandonment imposed by Brazilian public policies³. It is not predicable at this point if illegal and unsafe abortion will increase among women from the second generation of the epidemic.

My argument is that the scientific controversy about the causes of the congenital syndrome does not justify the failure by the state to assure the fundamental rights of these women. Such negligence further aggravates a perverse violation of human rights. Ethnographic presence has shown me how the epidemic produces more precariousness in lives already made vulnerable by social inequality and sexual discrimination. Therefore, I assume a prescriptive ethical tone to conclude this article: for the women of the second generation infected by the Zika virus, it is necessary to ensure access to information and family planning, with long-term contraceptive methods (currently not provided by Brazilian health policy), in addition to the right to terminate the pregnancy. Access to information and family planning are two health principles and rights provided by the 1988 *Brazilian Constitution*. The women of the first generation have unmet needs for social protection, the most urgent of which are conditions for survival and transportation to health care facilities. There is ongoing intersectional discrimination in the way the epidemic crosses the lives of these women^{9,10}: they were already poor, Northeast inhabitants, with low levels of education, and weakly integrated into the labor world; now, they are also caregivers of children with needs that are not protected by the Brazilian state.

1. Centro de Operações de Emergências em Saúde Pública sobre Microcefalias, Ministério da Saúde. Monitoramento dos casos de microcefalias no Brasil. Brasília: Ministério da Saúde; 2016. (Informe Epidemiológico, 17) (Semana Epidemiológica 10/2016, 05/03 a 12/03/2016).
2. Miranda-Filho DB, Martelli CMT, Ximenes RAA, Araújo TVB, Rocha MAN, Ramos RCF, et al. Initial description of the presumed congenital Zika syndrome. *Am J Public Health* 2016; 106:598-600.
3. Diniz D. Zika. Documentário. <https://www.youtube.com/watch?v=j9tqt0jaoG0> (accessed on 16/Apr/2016).
4. Rubin EJ, Greene MF, Baden LR. Zika virus and microcephaly. *N Engl J Med* 2016; 374:984-5.
5. Tetro JA. Zika and microcephaly: causation, correlation, or coincidence? *Microbes Infect* 2016; 18:167-8.
6. Sasaki RK. Eufemismo na contramão da inclusão. *Reação (Revista Nacional de Reabilitação)* 2010; XIV:14-7.
7. Cavarero A, Butler J. Condição humana contra "natureza". *Revista Estudos Feministas* 2007; 15: 650-62.
8. Brasil P, Pereira Jr. JP, Raja Gabaglia C, Damasceno L, Wakimoto M, Ribeiro Nogueira RM, et al. Zika virus infection in pregnant women in Rio de Janeiro: preliminary report. *N Engl J Med* 2016; [Epub ahead of print].
9. Corte Interamericana de Derechos Humanos. Caso Gonzáles Lluy y otros v. Ecuador. Demandante: Talía Gabriela Gonzales Lluy y otros. Demandado: Estado del Ecuador. Relatores: Juez Humberto Antonio Sierra Porto y otros. San José, 1 de septiembre de 2015. Corte Interamericana de Derechos Humanos. http://www.corteidh.or.cr/docs/casos/articulos/resumen_298_esp.pdf (accessed on 24/Feb/2016).
10. Lugones M. Colonialidad y género. *Tabula Rasa* 2008; (9):73-101.

Submitted on 22/Mar/2016

Final version resubmitted on 23/Mar/2016

Approved on 06/Apr/2016