Zika virus – the glamour of a new illness, the practical abandonment of the mothers and new evidence on uncertain causality

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A new epidemic in an old context of structural inequities

To appraise the impact of the Zika virus epidemics, we need to understand the challenges to reproductive justice posed by this new disease in a context of structural inequities. In August 2014, an outbreak of an illness with a flat pinkish rash, joint pain, bloodshot eyes, fever and headaches started in Natal, Northeast Brazil. Testing ruled out dengue and other potential causes. By March 2015, the illness had appeared in three different states, and in May 2015, researchers found that it was an outbreak of the Zika virus, transmitted by the same mosquito that is the vector for dengue and chikungunya viruses, the Aedes aegypti. 1

Zika infection was previously associated with neurological complications, such as Guillain-Barré syndrome (GBS) in a few cases, but up to that moment, was generally thought as a relatively benign illness, a type of a “soft dengue”. By September 2015, medical providers in the States of Paraíba and Pernambuco reported increased cases of microcephaly and cerebral calcifications. Other illnesses were ruled out, and the tests for Zika virus were positive in the amniotic fluid of affected pregnant women in mid-November. 2 In the following months, thousands of suspected cases of microcephaly and other neurological malformations emerged in Brazil, creating a global concern on this new public health and reproductive threat.

In February 2016, looking in particular at the strong association, in time and place, between a rise in detected cases of congenital malformations, neurological complications and infection with the Zika virus, the World Health Organization considered that the situation met the conditions for a Public Health Emergency of International Concern. 3 The scientific interest in this new public health emergency led to an explosion of publications on the biological, epidemiological and clinical aspects, and on establishing the causality links between the virus and the congenital syndrome. In April 2016, a WHO report noted that “microcephaly and other fetal malformations potentially associated with Zika virus infection or suggestive of congenital infection” were reported in Brazil (1046 cases), Cape Verde (2 cases), Colombia (7 cases), French Polynesia (8 cases), Martinique (3 cases) and Panama (1 case). There were two additional cases, linked to a stay in Brazil. 4 The series of neurological harms associated with the Zika virus was called congenital Zika syndrome (CZS).

Although Zika virus has spread throughout Brazil, Latin America and other regions, the concentration of high rates of microcephaly has been reported only in the Northeast of Brazil, and basically in poorer areas. By mid-2016, evidence suggested that Zika can cause microcephaly, but the clustering pattern hints that other environmental, socio-economic or biological factors could be at play. 5

Cases were concentrated in areas where there is little or no sanitation, with open sewage, and without a regular supply of clean drinking water (leading to the need to store water, a potential breeder for the mosquitoes). The environmental exposure to the Aedes also leads to an additional vulnerability to reproductive harms, as pregnant women are in contact with a superimposition of other infections (dengue and chikungunya, as the
most obvious), repeated fumigations with insecticides such as Malathion (known as neurotoxic and carcinogenic in humans), and drinking water treated with larvicides such as Pyriproxyfen, introduced in the region in 2014. It has been known for many years that frequent exposure to these substances results in insects developing mechanisms of resistance to insecticides and larvicides, as has been occurring with A. aegypti, leading to decreased effectiveness of these agents and the need to increase their concentrations, which are much higher in areas with little or no sanitation where the poorer population lives.

The effect of these substances on human reproduction is poorly understood, and their potential biological synergy is not properly contemplated in the research agenda. A report published by WHO about the safety of drinking water treated with Pyriproxyfen, using rats and rabbits as animal models, showed an increased frequency of skeletal variations and visceral anomalies in some of the concentrations tested for developmental toxicity; in rabbits, signs of maternal toxicity include an increased number of stillbirths and a reduction in the number of implantations, in the mean number of live fetuses, of abortion and premature delivery. The report concluded that the product was safe for humans. The Pyriproxyfen use in Brazil is unprecedented; it has never before been applied to a water supply on such a scale. Claims that it is not being used in Recife, the epicentre of microcephaly cases, have not been adequately confirmed.

Some evidence that other agents may be involved in the development of Zika-related neurological malformations in Brazil has recently emerged. Concerning microcephaly and other neurological malformations, studies in progress point to the possibility of association between the Zika virus and the bovine viral diarrhea virus, a pestivirus known to produce neurological birth defects in farm animals, but believed to be innocuous in humans.

In addition to these risks, a number of concurrent events have occurred in Brazil, each of which provides an alternative hypothesis worth exploring to understand these geographic differences for microcephaly. Some of the suspected aetiologies, based on pregnant women's recent exposure, include: adverse effects of medical technologies introduced in 2014, such as pestivirus contamination in pertussis vaccine; glyphosate toxicity in bovine products in TdaP, a booster immunisation against tetanus, diphtheria and pertussis (via interactions with aluminium in the vaccine); horizontal transfer of piggyBAC transposon from released genetically modified mosquitos; pre-natal vitamin folic acid toxicity in gene mutation carriers, and interactions among any of the above.

The most effective and safe public health strategy to deal with vector-borne epidemics is basic sanitation with a regular supply of treated water, and it should be prioritised over a chemical-based vector control. This is particularly true for countries like Brazil where, due to insect resistance to the products, different substances are rotated in the field or their doses are increased, and the presence of mosquitoes keeps increasing regardless of changes of drugs or use of higher concentrations. The effect of 30 years of chemicals-based vector control strategy is that the Brazilian population is more vulnerable than ever, with the territorial expansion of the A. aegypti infestation in the country attesting this failure. Poorer women of reproductive age are disproportionately represented among those who live in these environmentally vulnerable areas.

The Zika epidemics has widened the inequity and limitation of women’s health and rights, in two main aspects: their reproductive rights to regulate their fertility, and the support they need to care for a child with the CZS.

**The affected women and the context of their reproductive rights**

Reproductive rights in Brazil are limited and abortion is illegal, except in the case of rape, to save the woman’s life, and in some cases of anencephaly. There is an absence of safe abortion policies for Zika-affected women who would choose to terminate the pregnancy, if they were uncertain of the potential consequences and do not want to run the risk of having a severely malformed child, or even for those who have a confirmed affected pregnancy. Furthermore, the possibility of the diagnosis of harms to the baby is usually late in pregnancy, which renders it impossible to wait for confirmation of the severity of the case. This is particularly difficult for those women with low income and education, who already have limited access to contraception, have the highest rates of unwanted pregnancies, and cannot afford the cost of an illegal, safe abortion, available only in clandestine and expensive clinics.
The Zika epidemic demanded rethinking the restrictive Brazilian legislation. The National Association of Public Defenders has filed a lawsuit in the Federal Supreme Court, requesting the right to abortion for pregnant women diagnosed with the Zika virus, based on women’s mental suffering, especially because the diagnosis of microcephaly may be late (after the 20th week). The action also deals with the right to information, guarantee of long-term contraception, social protection and transportation for the unlimited needs for several forms of special care for the affected babies. The constitutional claim was presented before the Supreme Court, which has a history of evolving recognition of women’s reproductive rights in previous cases.

Any initiative for expanding abortion rights does not face a good moment, however, as at present Brazil has possibly the most religious and conservative Congress ever, a federal government with limited legitimacy and many ties to the most reactionary and misogynistic sectors. On 29 November 2016, the Brazilian Supreme Court met to decide the case of a woman and the staff of an (illegal) abortion clinic in preventive prison, and the ministers unanimously understood that imprisonment was not justified, because the necessary requirements for the enactment of pre-trial detention were not present. Additionally, one of the ministers Luís Roberto Barroso, cast his vote considering that the criminalisation of abortion before the third month of gestation violates women’s autonomy, the right to physical and mental integrity, women’s sexual and reproductive rights, gender equality, as well as provoke social discrimination and a disproportionate impact of criminalisation on poor women. Unsurprisingly, the Congress reacted instantaneously to the decision of the Supreme Court, promising to reverse the judgement and prevent the use of this sentence as jurisprudence.

The glamour of the new virus, and the practical abandonment of women

Women are tormented by the lack of support with caring for the affected children. As eloquently shown in Debora Diniz’s film “Zika, a documentary” and in her book “ZIKÁ – From the Northeastern Inlands to Global Threat” (“Zika – do Sertão Nordestino a Ameaça Global”, both in in Portuguese), the lives of these women have been redefined by this kind of motherhood: the great interest in the new illness, and the practical abandonment of the mothers. Clinics specialised in microcephaly with well-trained providers are put in place, but there is very little support for the mothers and families themselves to deal with a child with permanent disabilities.

They face the fear of an uncertain diagnosis, the multiple repeated imaging tests, and the daily challenge of caring for a baby with numerous special needs in a context of great social vulnerability. The inequality to which these women are subjected in their life contexts, exacerbates the already deteriorated situation of access to health services. There is a wide range of clinical conditions, ranging from borderline situations to severe neurological malformations in these children. Often, these babies are very irritable and many cry inconsolably all day long, and end up being heavily sedated. Cohabitation in these situations is extremely painful, and not infrequently, husbands leave their wives and families after the birth of these children. The mothers of these babies who already have other children say that they have abandoned the rest of their offspring, since they have to dedicate themselves totally to the sick child.

In order to be entitled to a cash transfer scheme for families with members in special needs, called Continuous Benefit Program, they must earn not more than a quarter of the minimum wage per family, which implies proving extreme poverty, which prevents many poor women receiving this financial support. Indeed, family income is further diminished by the reality of women who have to leave their paid work to devote themselves exclusively to the affected child.

Health services were organised to address the needs of affected populations, within the Public Health System (SUS), including rehabilitation services, aiming to provide early stimulation for the babies to try to compensate for the neurological damage, with variable effectiveness. These women need to travel, sometimes hundreds of miles, with their babies for physiotherapy sessions, and depend on the goodwill of municipal services for transportation.

If on the one hand, women seem to be the main victims of Zika virus in Brazil, on the other hand they emerge as leaders and entrepreneurs of supportive initiatives. They start to meet through the health services, keep in touch and organise themselves by social media – even the poorest ones have mobile phones. They put together the
Association of Mothers and Rare Families, AMAR, in Pernambuco, and also the Union of Mothers of Angels (UMA), which already has more than 300 subscribers. Through public events and social networks, the group promotes actions to combat prejudice, collects donations and provides assistance to mothers and babies affected by the syndrome. They also provide invaluable peer support of mothers with the same problem, to help each other and together think about their situation, as they are in a privileged position to imagine solutions to their problem. These movements learn from and join the existing activism of mothers of children with disabilities, which were less visible before the great interest raised by the Zika epidemics.

In a moment of great restriction of public policies in Brazil, including the recently approved freeze on public spending on health and education for 20 years, the creation of specialised services for the affected babies, mothers and families is extremely needed and have to be treated as a priority. In a reproductive justice perspective we should consider the Zika virus crisis in the context of reproductive stratification, gender inequalities, and social justice, to understand the human implications of the epidemics.

New evidence: no continuing association between Zika infection and microcephaly?

In April 2017, a report by researchers of the Brazilian Ministry of Health and of the Pan American Health Organization was published describing striking news. In view of the apparent resurgence of Zika infection and GBS early in 2016, a further increase in the cases of microcephaly was anticipated in the year – but this expected resurgence did not happen. The authors raised three hypothesis to explain this apparent paradox; first, that there was another arbovirus (dengue virus, chikungunya virus or another), also transmitted by the A. aegypti, that could be associated with the malformations; second, that the Zika virus infection was a necessary but not a sufficient condition for the so-called CZS; and third, that there were additional pregnancy terminations in Brazil. Starting in the second half of 2016, a slight decline in live births was visible in Brazil in the Live Birth Registration System (SINASC), especially in the more affected states, possibly indicating that at least some women were changing their fertility behaviour during the period of the Zika virus epidemic. Part of this decline could also be attributed to the economic and political crisis in Brazil. But none of these factors explain the sharp and unexpected decline in microcephaly within the epidemics.

The decline in microcephaly was really striking news, as hundreds of papers and research initiatives have been published or launched in response to the novel relationship between the Zika virus and the CZS, since the World Health Organization considered the situation a Public Health Emergency of International Concern in February 2016. In November 2016, the World Health Organization declared an end to its global health emergency over the spread of the Zika virus. The WHO stressed that the virus “remains a significant enduring public health challenge requiring intense action”. On 11 May 2017, the Ministry of Health of Brazil declared that the Zika National Public Health Emergency (NPHE) may be over.

Conclusion

Regardless of the causality relations between the Zika virus and the so called CZS, there is a CZS affected population that dramatically needs the appropriate responses. This is even more needed in a context of uncertainty, which brings additional suspense and precariousness. Together with the already unmet reproductive needs of safe and socially supported contraception, abortion, childbirth and childbearing, new illnesses and challenges demand innovative approaches, from primary prevention to rehabilitation, and these innovations should include women’s rights and empowerment as a top priority. This can happen in many instances, from finally implementing the imperative solutions of basic sanitation with a regular supply of treated water, to training and empowering women and family members in remote areas to provide themselves with stimulation care, with providers acting as their coaches and supervisors (reducing the burden of long trips to access care). Other actions are providing good quality health care (including the reproductive needs of mothers), and giving psycho-social and financial support to women and families affected by this public health and reproductive disaster.

These are new elements in an already uncertain landscape for public health initiatives, and both emergency and permanent policies to
support the mothers and families of the affected children are urgently needed. Reproductive justice should be much more than the right to decide when to have a child – it should include the necessary recognition of the economic, social and emotional overburden of caring for children in general, and particularly for those who have special needs.

**Disclosure statement**

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