

Ethics, global health and Zika virus infection: a view from Brazil

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Abstract

The emergency of the Zika virus outbreak, with the risk of a presumed congenital syndrome and other events connected with its neurotropism, as well as unequal access to diagnostic and health care resources for the affected present a scenario with several ethical concerns. This paper discusses three ethical issues related to the Zika virus infection. The first one refers to the relationship between Brazilian states in a particular geopolitical context of “public health emergency of international concern”. The second one covers the balance between individual freedom and rights, and the need for State intervention. The third one refers to women’s right to choose abortion, and to the assistance for a legion of children with neuropathic syndromes and their families. To cope with a possible pandemic disease in a world without boundaries, we should set up international cooperative teams, deal with different cultural approaches regarding the balance between individual and collective rights, and the consequences to assistance and public policies.

Keywords: Bioethics. Zika virus infection. Communicable diseases, emerging. Global health. Brazil. Public health policy. Internationality.

Resumo

Ética, saúde global e a infecção pelo vírus Zika: uma visão a partir do Brasil

A emergência da epidemia pelo vírus Zika, com risco da síndrome congênita e outros eventos relacionados com seu neurotropismo, bem como o acesso desigual a recursos para diagnóstico e cuidados de saúde, constitui cenário com várias preocupações éticas. Abordamos três questões relacionadas com a infecção pelo Zika vírus. A primeira refere-se às relações entre os Estados nacionais num contexto geopolítico particular de “emergência de saúde pública de preocupação internacional”; a segunda, ao equilíbrio entre liberdade e direitos individuais e a necessidade de intervenção do Estado; a terceira, ao direito das mulheres de escolher o aborto e a assistência para uma legião de crianças com síndromes neuropáticas e suas famílias. Para lidar com uma pandemia em um mundo sem fronteiras, devemos criar equipes internacionais cooperativas, lidar com diferentes abordagens culturais sobre o equilíbrio entre direitos individuais e coletivos e suas consequências para a assistência e políticas públicas.

Palavras-chave: Bioética. Infecção pelo Zika vírus. Doenças transmissíveis emergentes. Saúde global. Brasil. Políticas públicas de saúde. Internacionalidade.

Resumen

Ética, salud global y la infección por el virus Zika: una visión desde Brasil

La aparición de la epidemia por el virus Zika con el riesgo de síndrome congénita y otros eventos relacionados con el neurotropismo del virus, así como el acceso desigual a los recursos para el diagnóstico y cuidado de la salud constituyen un escenario con varias preocupaciones éticas. Este artículo analiza tres cuestiones éticas relacionadas con la infección por este virus. La primera se refiere a las relaciones entre los estados nacionales en un contexto geopolítico particular de “emergencia de salud pública de preocupación internacional”. La segunda al equilibrio entre la libertad y los derechos individuales y la necesidad de intervención del Estado. La tercera al derecho de la mujer a aborto y la asistencia a una legión de niños con síndromes neuropáticos y a sus familias. Para hacer frente a una posible pandemia en un mundo sin fronteras, debemos crear equipos internacionales en base cooperativa, que trata de diferentes enfoques culturales para el equilibrio entre los derechos individuales y colectivos y sus consecuencias para la asistencia y la política pública.

Palabras clave: Bioética. Infección por el virus Zika. Enfermedades transmisibles emergentes. Salud global. Brasil. Políticas públicas de salud. Internacionalidad.

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Declaram não haver conflitos de interesse.

Background

The Zika virus (ZIKV) was first isolated in 1947 in rhesus monkeys in the Zika forest in Uganda. In 1948, it was found in the *Aedes* mosquitoes and in 1952 isolated in humans. In 2007, the first outbreak was described on a small island in Micronesia. In 2013, there was a second outbreak in French Polynesia. The third major outbreak of the infection began in northeastern Brazil in May 2015 and it is still ongoing. In October 2015, fourteen Brazilian states reported cases of the infection and autochthonous related cases were reported in Colombia.

In October 2015, cases of microcephaly began to be investigated in northeastern Brazil to verify the hypothesis of an association with the ZIKV¹. On Feb 1, 2016, the World Health Organization (WHO), under the international health regulation of 2005, ranked the Zika epidemic as a *public health emergency of international concern*². In a study with retrospective outbreak data in French Polynesia it was estimated that *the risk of microcephaly was of 95 cases (95 CI 34-191) per 10,000 women infected in the first trimester of pregnancy, corresponding to the ratio of 53.4 risk (95% CI 6.5-1061.2)*³. In January 2016, there were reports of infection in Latin America and the Caribbean associated with an increase in cases of microcephaly⁴.

The ZIKV infection is a mild disease, but it can manifest itself with higher severity in cases of consequent congenital Zika syndrome and Guillain-Barré syndrome. Being a disease with no known effective treatment, no vaccine available and with many uncertainties to be investigated, it is necessary that the research is done by observing the high ethical standards required. The fears of the affected population and industry interests are also factors that can influence as secondary interests the ethical evaluation of the research. In this context, Brazil has a strict system of ethical evaluation that must adapt to the reality of a health emergency, but without giving up the essential care in protecting individuals and populations. It is important to remember, however, that this may not be the reality of other peripheral countries.

Some ethical issues related with Zika virus infection

The general context in which we will start this discussion about emerging diseases is economic globalization, and from a geopolitical perspective.

We will then discuss an issue that may seem basic for many of us, that is the possible limitation of individual freedoms and rights from a perspective of collective protection within health policies. Finally, we discuss moral issues related to ZIKV infection during pregnancy, looking at the example of fetuses diagnosed with microcephaly. We will also address two moral issues associated with it: the possibility of abortion and the assistance required for a child with severe neuropathy in Brazil.

Our colonial past explains what the Brazilian playwright Nelson Rodrigues once termed "*complexo de vira-latas*". An American journalist translated this expression as "the mongrel complex"⁵, but we believe "the mutt complex" is a more appropriate translation. Although Rodrigues initially used this term to refer to emotions arising from the defeat of the Brazilian soccer team in the 1950 World Cup, it has a much broader application. Rodrigues' original concept is present in that of coloniality, as expressed by Quijano in 1997⁶. Although he specifically focuses on Latin America, we consider that this could also apply to Africa. Coloniality is understood as something that transcends colonialism itself (i.e., post-independence or the end of the colonial relationship) and is configured to maintain subordinate relationships in a cross-border capitalist system. The colonization model represents not only economic domination but also cultural domination. Assis comments on this point as follows:

*The construction of hierarchies of race, gender and modes of appropriation of natural resources, can be seen as contemporary to the establishment of an international division of labor and territories, marked by asymmetrical relationships between centric and peripheral economies. From the perspective of coloniality, the old colonial hierarchies, which were grouped in European versus non-European, remained entrenched and entangled in the international division of labor*⁷.

Within this perspective, the national economic elites do not antagonize international interests; rather, their dependence articulates them. Their actions perpetuate the colonial ideology, expressed here by the idea of the mutt complex, which represents the "natural" disqualification of miscegenation.

We understand that in this general context, the crisis of immigrants from Africa and the Middle East (e.g., war, political and economic refugees) can also be understood as consequences of the colonial model and coloniality. Boaventura de

Souza Santos⁸ understands that this seems to be an abyssal line, keeping large segments of the world population invisible. The Spanish philosopher Adela Cortina discusses “aporofoby” (from the Greek *aporos*, meaning without resources, poor, and *fobos*, fear) as meaning the fear of or hostility to poverty or the poor⁹. From this perspective, “moral disengagement”¹⁰ arises, when individuals or groups of individuals admit moral exceptions to justify discriminatory behavior to individuals and/or social groups. We must face this situation with courage and without euphemisms.

We introduce this debate on international relations to draw attention to the fact that countries that are now at the center of the events related to the infection by ZIKV have a continuous history of unequal and at times unfair economic relationships. Thus, if we intend to undertake righteous action, increasingly frequent global health crises must be met with directed efforts to overcome coloniality. In this sense, multinational organizations, such as the United Nations and the WHO are prime locations for multilateralism. This means to respect and support all countries to become strengthened — in political, economic and technical terms — to cope with emerging and re-emerging diseases. It must be understood that sick people inhabit real countries, which must deal with their own cultural and organizational issues that interfere with their public health actions.

What is the best way to limit the spread of emerging diseases? Will the control of borders be sufficient? The best course of action for international assistance is to support affected countries to cope with such emergencies. But then how should support be provided? Possible assistance could come via technology transfer, the creation of multinational research groups with respect to local traditions (including local research teams) and by ensuring that all members can be considered peers on equal terms. We understand that *inequality destroys not only in unequal countries such as Brazil but also in an unequal world*.

We will now analyze the possible conflicts between the values recognized as relevant to our society and some public health actions when facing sanitary emergencies. In general, medical paternalism and even state paternalism (or authoritarianism) minimize the ability and desire of individuals to make decisions about their own lives. Such individuals are usually perceived as incompetent, lacking technical information, without the appropriate scholastic instructions,

or as possessing alleged cognitive or emotional disabilities. We understand these manifestations as being ingrained prejudices in the ruling classes and often incorporated by disadvantaged sectors of society by mechanisms of power and domination.

However, the reality is more complex still, especially when the relationship between public interest and individual interests can result in conflict. Recently, in one of the universities here in Rio de Janeiro, a case went to a hospital committee for discussion as no consensus had been reached on what action to take. The case concerned a woman, a patient at the university hospital with multidrug-resistant tuberculosis, who did not accept the proposed treatment or advice to stay in isolation. After intense discussions on the need to protect society and to act to implement a compulsory treatment and/or hospitalization in isolation, committee members concluded that they should not impose treatment on those who do not want it, even after being fully advised of the consequences of this decision for her and society. What is most interesting in this case is that there exists a long-standing WHO procedure for such cases: Directly Observed Therapy¹¹.

A paradox exists — while doctors and governments tend to act in a paternalistic or authoritarian way toward low — income populations in general, they greatly respect the freedom and autonomy of the richest 1%. In fact, they do not seem to be prepared to make public decisions on issues related to health in which the collective interest conflicts with individual interests. Furthermore, even when they take appropriate measures, they do not appear to be sufficiently consequential to monitor the implementation of these actions and enforce such decisions. How should these issues be dealt with in a country where public discussion and public ethics in health are not the norms, and where professionals make decisions and often do not justify them publicly? What is the limit when individual freedoms can, or should, be restricted?

Although there is a regulatory framework in Brazil to enable actions in situations that are declared health emergencies, for other such actions (e.g., compulsory vaccination), there are no effective control mechanisms. It does not seem reasonable then, that these measures should be effectively imposed by force and mechanisms of coercion. The main strategy should be to elucidate and to convince, and therefore, the use of mass media is essential.

However, this communication strategy must also be enlightening and respectful of individuals. There are some, here and elsewhere, who are wary of government actions or simply advocate more natural strategies to combat or prevent diseases. How many, for example, in the United States are mobilizing to combat vaccines with arguments that are not scientifically valid?

So, again, we ask: Is it possible to respect individual freedom in situations of health emergencies? Can we use the argument of the need to protect the most vulnerable against the abuse of individual decisions that are potentially harmful to society? The answer is *yes*. Even Stuart Mill, for whom individual freedoms are the fundamental principle of adult humans, said in his classic essay "On liberty", *the only purpose for which power can be exercised rightfully over any member of a civilized community, against his will, is to prevent harm to others*¹².

The general orientation presented by the Nuffield Council on Bioethics is very reasonable about this issue and can be a starting point for our preparation in this crisis: *Choice of policy should be proportionate: the least intrusive measure that will achieve the desired aim should be preferred. The more intrusive the approach, the greater the justification required*¹³. To this we add: and the better the communication should be. The question is how to translate this in a country with such substantial inequalities, with different levels of access to resources. This is part of the challenge we face and present to Brazilian society and the world.

The third and final point we will address relates to the neurological damage associated with infection by ZIKV during pregnancy. The severity of clinical conditions that have been described by medical assistants and researchers means that we can infer that there will be a serious impact on the development of affected children. The studies that are being developed will enable researchers to understand the evolution of these cases and to recognize the degree of neurological impairment that these children present^{14,15}.

The debate on abortion in Brazil is largely detrimental to the poorest women who find themselves prevented from having access to safe abortion processes with appropriate resources. In contrast, those women who can pay for terminations can do so safely and without major risks. No woman should be forced to have an abortion nor prevented from doing so if that is her wish. The hypocrisy with which the subject is treated in Brazil

must be addressed, if possible with international support. According to the UN High Commissioner for Human Rights, Zeid Ra'ad Al Hussein, *health services must be delivered in a way that ensures a woman's fully informed consent, respects her dignity, guarantees her privacy, and is responsive to her needs and perspectives*¹⁶. He further adds, *laws and policies that restrict her access to these services must be urgently reviewed in line with human rights obligations to ensure the right to health for all in practice, and comprehensive sexual and reproductive health services include contraception – including emergency contraception – maternal health care and safe abortion services to the full extent of the law*¹⁶.

In cases where the woman chooses to continue the pregnancy to term under the suspicion of Zika infection or is prevented from having an abortion, a serious problem arises: the quality of care that will be available to these children and their families, in the quite likely event of serious injury, has severe limitations. Our society is particularly perverse in such cases: the problem is seen as the sole responsibility of the family, or even just that of the mother. The policies that have been proposed to address this situation are clearly insufficient: significantly low financial aid is provided only for very poor families; and the training of physical therapists in early stimulation and symptomatic treatment at health units.

The present framework ensures that children in these conditions and their mothers will experience a life of great hardship. The mothers will have to stop working because there are no suitable institutions to receive these children (e.g., day-stay hospitals as an appropriated day care center). These children will probably stay at home or be 'looked at' by neighbors or older siblings because the parents cannot leave their work without severely reducing their own standards of living. We do not have the infrastructure to accommodate these children and their families, to ensure them a minimum level of dignity in their survival.

Final considerations

International cooperation is welcome and necessary, and should promote the development of local potential and expand the understanding of the diversity of the world.

What can we expect with this scenario? Difficult times for all of us, but especially for the

poorest persons. We need to better control the situation, be prepared to help and protect our population. This is the moral duty of humankind. The Zika virus infection brings, as most emerging

or re-emerging diseases, some moral questions. Future generations will judge us as to how we deal with them today, by our ability and capacity to act ethically and consistently.

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Participação dos autores

Sergio Rego wrote the first draft of this article, which was revised and augmented by Marisa Palacios. Successive revisions were made until we reached a final consensus.

