



Ministério da Saúde

FIOCRUZ

Fundação Oswaldo Cruz



Ilana Grunbaum Ambrogi

Justiça reprodutiva e a epidemia do vírus zika no Brasil: questões éticas urgentes em emergências de saúde pública

Rio de Janeiro

2021

Ilana Grunbaum Ambrogi

Justiça reprodutiva e a epidemia do vírus zika no Brasil: questões éticas urgentes em emergências de saúde pública

Tese apresentada ao Programa de Pós-Graduação em Bioética, Ética Aplicada e Saúde Coletiva, da Escola Nacional de Saúde Pública Sergio Arouca, na Fundação Oswaldo Cruz, como requisito parcial para a obtenção do título de Doutor em Bioética, Ética Aplicada e Saúde Coletiva, em regime de associação com a Universidade Federal do Rio de Janeiro, a Universidade do Estado do Rio de Janeiro e a Universidade Federal Fluminense.

Orientadora: Prof.^a Dr.^a Debora Diniz Rodrigues.

Rio de Janeiro

2021

Título do trabalho em inglês: Reproductive justice and the Zika epidemic in Brazil: urgent ethical issues in public health emergencies.

This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) – Finance Code 001.

Catálogo na fonte
Fundação Oswaldo Cruz
Instituto de Comunicação e Informação Científica e Tecnológica em Saúde
Biblioteca de Saúde Pública

A495j Ambrogi, Ilana Grunbaum.
 Justiça reprodutiva e a epidemia do vírus zika no Brasil: questões éticas urgentes em emergências de saúde pública. / Ilana Grunbaum Ambrogi. -- 2021.
 91 f.

 Orientadora: Debora Diniz Rodrigues.
 Tese (Doutorado) – Programa de Pós Graduação de Bioética, Ética Aplicada e Saúde Coletiva. Escola Nacional de Saúde Pública Sergio Arouca, Rio de Janeiro, 2021.

 1. Direitos Sexuais e Reprodutivos. 2. Zika virus. 3. Vulnerabilidade Social. 4. Emergências. 5. Saúde Pública. 6. Direitos Reprodutivos - ética. 7. Disparidades nos Níveis de Saúde. 8. Brasil. I. Título.

CDD – 22.ed. – 614.58850981

Ilana Grunbaum Ambrogi

Justiça reprodutiva e a epidemia do vírus zika no Brasil: questões éticas urgentes em emergências de saúde pública

Tese apresentada ao Programa de Pós-Graduação em Bioética, Ética Aplicada e Saúde Coletiva, da Escola Nacional de Saúde Pública Sergio Arouca, na Fundação Oswaldo Cruz, como requisito parcial para a obtenção do título de Doutor em Bioética, Ética Aplicada e Saúde Coletiva, em regime de associação com a Universidade Federal do Rio de Janeiro, a Universidade do Estado do Rio de Janeiro e a Universidade Federal Fluminense.

Aprovada em: 26 de março de 2021.

Banca Examinadora:

Prof^ª. Dra. Roberta Lemos dos Santos
Instituto Federal do Rio de Janeiro

Prof^ª. Dra. Luciana Stoimenoff Brito
Instituto de Bioética, Direitos Humanos e Gênero

Prof^ª. Dra. Marisa Palácios da Cunha e Melo de Almeida Rego
Universidade Federal do Rio de Janeiro

Prof. Dr. Sergio Tavares de Almeida Rego
Fundação Oswaldo Cruz - Escola Nacional de Saúde Pública Sérgio Arouca

Prof^ª. Dra. Debora Diniz Rodrigues (Orientadora)
Fundação Oswaldo Cruz - Escola Nacional de Saúde Pública Sérgio Arouca

Rio de Janeiro

2021

To women and girls.

AGRADECIMENTOS

I would like to thank and acknowledge the extraordinary debt I owe to several people that made these past few years and this dissertation possible. From sharing and exchanging of ideas, readings and lectures, to the review of the work, mentorship, computer assistance, partnership and friendship, and very importantly, meal sharing and gatherings. It is and it was the intersection of this ample network of support that made this all possible. I would like to show my gratitude to Debora Diniz and Luciana Brito for the tireless attention and endless generosity. To Professors Sergio Rego and Marisa Palacios. To Gabriela Rondon, Martha Ysis, Sinara Gumieri and all at Anis-Institute of bioethics. To Claudio Neto, Renné Ambrogi, David Ambrogi, Roberta Lemos and family, Reina (*in memoriam*). To the Gruenbaum family: Paulo, Tia Ivone, Tio André (*in memoriam*), Suzana and family, Daniel and family. To Marie Flores, Eugene Schiff, Kathi Funk and Hima Ekanadham. To the PPGBIOS Program and all the colleagues, staff and faculty. To Pablo Fortes, Veronica Santana Queiroz, Amiel M. Vieira, Irene Lopez, Lucas Lopes, Dionisio Furtado Jr., Maria Clara Neimeyer. To Professors Suely Marinho, Miriam Ventura, Lilian Koifman. To all the women who taught me so much along these years. For all the generosity and kindness. For making the world bigger. To all my sincere and deepest thank you.

We know of course there's really no such thing as the 'voiceless'. There are only the deliberately silenced, or the preferably unheard.

It is becoming more than clear that violating human rights is an inherent and necessary part of the process of implementing a coercive and unjust political and economic structure on the world. Without the violation of human rights on an enormous scale, the neo-liberal project would remain in the dreamy realm of policy. But increasingly human rights violations are being portrayed as the unfortunate, almost accidental fallout of an otherwise acceptable political and economic system.

Arundhati Roy, 2004, Sydney Peace Prize.

RESUMO

O argumento central desta tese é que o patriarcado operou para desviar o foco daquelas mais afetadas pela epidemia de Zika – mulheres e meninas em idade reprodutiva. E, desse modo, aprofundando vulnerabilidades preexistentes que se ancoram na desigualdade de gênero. Esta tese se baseia na compreensão do gênero como um regime político onde o patriarcado atua para manter as desigualdades sob a justificativa de que haveria uma hierarquia de gênero. Esta é uma pesquisa que utiliza-se de lentes feministas para uma análise bioética sobre como as assimetrias de gênero têm efeitos para a vida de mulheres, meninas e comunidade. A doença transmitida pelo vírus zika era pouco conhecida até 2015. Em razão de suas consequências para mulheres grávidas e fetos – especialmente meninas e mulheres vivendo no nordeste do Brasil, em 2016 a Organização Mundial da Saúde declarou Emergência de Saúde Pública de Interesse Internacional. Atualmente sabe-se que o vírus Zika causa a síndrome congênita do Zika, como consequência da infecção congênita devido à transmissão do vírus da mulher grávida para o feto. Além disso, também é sabido que o vírus é transmitido sexualmente. Zika acabou sendo o primeiro arbovírus conhecido a ter consequências sexuais e reprodutivas. Esta tese é composta por três artigos científicos e um editorial que apresenta resultados de estudos que investigam os efeitos da epidemia de zika nas vidas de mulheres. Argumentamos que a desigualdade de gênero contribuiu para os efeitos encontrados a seguir: 1- a epidemia de Zika piorou as vulnerabilidades sociais e econômicas de mulheres e meninas afetadas; 2- o surto de zika em um contexto em que há uma inadequação das respostas para garantia de saúde sexual e reprodutiva, contribuiu para uma maior vulnerabilização da vida de mulheres e meninas; 3- a assimetria de gênero e suas dinâmicas de poder impactaram a participação das mulheres em pesquisas e agravaram suas vulnerabilidades. O patriarcado impôs um apagamento do discurso público no tema da saúde e direitos sexuais e reprodutivos, incluindo o direito ao aborto. Este impedimento do discurso público no contexto de uma emergência de saúde pública devido a um vírus, cujo principal impacto é na saúde reprodutiva, tirou o foco daquelas que correm mais risco e são afetadas por ele: mulheres e meninas. Nesse sentido, a epidemia de Zika foi um estudo de caso sem precedentes que reforça que os direitos sexuais e reprodutivos, incluindo o direito ao aborto, devem ser uma questão central para justiça reprodutiva e igualdade de gênero em qualquer resposta a emergências de saúde pública.

Palavras-chave: direitos sexuais e reprodutivos, zika vírus, vulnerabilidade, emergência de saúde pública, justiça reprodutiva.

ABSTRACT

The central argument of this dissertation is that patriarchy operated to shift the focus away from those most affected by the Zika epidemic – women and girls of reproductive age – reifying vulnerabilities based on gender inequality. This dissertation is based on the understanding of gender as a political regimen where patriarchy acts to maintain gender inequalities based on the assumption of gender hierarchy. As such, this is a feminist approach to research and bioethical analysis where the examination of social inequality focuses on the evaluation of the effects of gender asymmetries in the individual and within the community. Zika virus is a mosquito-borne disease that was mostly unknown until the World Health Organization declared it a Public Health Emergency of International Concern in 2016 due to the effects of the Zika virus in the pregnancy and fetal development observed in women and girls living in the northeast region of Brazil. Zika virus was found to cause congenital Zika syndrome, as a consequence of the congenital infection due to the transmission of the virus from the pregnant women to the fetus. It was also found to be sexually transmitted. Zika turned out to be the first known arbovirus to have sexual and reproductive consequences. This dissertation is composed of three scientific articles and an editorial piece that present research findings done by investigating the effects of Zika on the lives of women directly impacted by the Zika epidemic. The following main aspects of gender inequality were revealed: 1- the Zika epidemic worsened the social and economic vulnerabilities of affected women and girls; 2- the Zika outbreak in the context of inadequate sexual and reproductive health rendered women and girls even more vulnerable; 3- gender asymmetry and power structure dynamics impacted women's research participation and aggravated their vulnerabilities. Patriarchy imposed an absence of public discourse regarding sexual and reproductive health and rights, including the right to abortion. This impediment of public discourse in the context of a public health emergency due to a virus whose major impact is on reproductive health shifted the focus away from those most at risk of and affected by it: women and girls. In this sense, the Zika epidemic was an unprecedented case study that reifies that sexual and reproductive rights, including the right to abortion, must be a central issue in any public health emergency responses as a matter of reproductive justice and gender equality.

Keywords: sexual and reproductive rights, Zika virus, vulnerability, public health emergency, reproductive justice.

LISTA DE ABREVIATURAS E SIGLAS

ADI	Ação Direta De Inconstitucionalidade
ADPF	Arguição de Descumprimento de Preceito Fundamentada
BPC	Benefício de Prestação Continuada
CAAE	Certificado de Apresentação de Apreciação Ética
COVID-19	Disease caused by SARS-CoV-2 virus
CT	Computerized Tomography
CZS	Congenital Zika Syndrome
DFID	Department For International Development
ECLAC	Economic Commission for Latin America and the Caribbean
HDI	Human Development Index
IRB	Institutional Review Board
Km	Kilometer
LAC	Latin America and the Caribbean
LAI	Lei de Acesso a Informação
MD	Medical Doctor
PhD	Doctor of Philosophy Degree
PHEIC	Public Health Emergency of International Concern
PNAD	Pesquisa Nacional por Amostra de Domicílios
SARS-COV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SINASC	Sistema de Informações sobre Nascidos Vivos
SUS	Sistema Único De Saúde
TORCH	Toxoplasmosis, Other Agents, Rubella, Cytomegalovirus, and Herpes Simplex
UNFPA	United Nations Population Fund
USD	United States dollars
WHO	World Health Organization

SUMÁRIO

1	INTRODUCTION	10
2	RESEARCH ARTICLES	22
2.1	THE VULNERABILITIES OF LIVES: ZIKA, WOMEN AND CHILDREN IN ALAGOAS STATE, BRAZIL.....	22
2.2	ZIKA PUBLIC HEALTH EMERGENCY IN BRAZIL: WOMEN AND SEXUAL AND REPRODUCTIVE HEALTH NEEDS.....	40
2.3	REFLECTIONS ON RESEARCH ETHICS IN A PUBLIC HEALTH EMERGENCY: LISTENING TO BRAZILIAN WOMEN AFFECTED BY ZIKA.....	56
3	EDITORIAL	76
3.1	RESEARCH ETHICS AND THE ZIKA LEGACY IN BRAZIL.....	76
4	FINAL CONSIDERATIONS	79
	REFERENCES	83

1 INTRODUCTION

During 2015 and 2016, Brazil gained international notoriety due to the outbreak of Zika virus infections, mostly concentrated in the northeast region of the country. In February 2016, the World Health Organization (WHO) declared the fourth public health emergency of international concern (PHEIC) in history due to the temporally related surges of Zika virus infections and cases of neurological complications and malformations in fetuses and newborns in the region (WORLD HEALTH ORGANIZATION, 2016a). Since then, the relationship of causality between the mosquito-borne Zika virus infection during pregnancy and congenital Zika syndrome (CZS) has been confirmed (MARTINES et al., 2016). Microcephaly was initially considered a necessary manifestation when considering a suspected CZS diagnosis (BRADY et al., 2019; DE OLIVEIRA et al., 2017). Later, we learned that the effects of congenital Zika infection on the fetus, child, and pregnancy have a wide range of manifestations that are not limited to microcephaly (MARTINES et al., 2016; RICE et al., 2018). During pregnancy, Zika infection can lead to placental changes, fetal death, and spontaneous abortion (MARTINES et al., 2016). Although the Zika virus is primarily transmitted by *Aedes* mosquitos, it has also been found to be sexually transmitted (BAUD et al., 2017; HILLS et al., 2016; PETERSEN et al., 2016). Thus, Zika turned out to be a novel viral infection to affect both the reproductive and sexual health of women in Brazil. No other arbovirus had ever been known to have such significant, longstanding, and irreversible reproductive consequences.

This dissertation is focused on exploring how marked gender, racial, social, and economic inequalities perpetuated by power structures based on white supremacist capitalist patriarchy (HOOKS, 2015) led Zika to disproportionately impact the lives of women and girls living in the poorest regions of Brazil (BRADY et al., 2019; DE OLIVEIRA et al., 2017). It analyses and discusses how the disregard for women's and girl's rights, particularly sexual and reproductive health, including the right to abortion, had an important role in erasing the Zika epidemic and its consequences from the political and public health agendas in Brazil. As feminist research, this work is based on the comprehension of gender as a political regimen that enables patriarchal systems of power to govern the lives and bodies of women and girls (DINIZ, 2014). A feminist bioethics perspective allows for a critical analysis of social inequalities as a way to more adequately understand the effects of gender asymmetries on the individual and communities (DINIZ; GUILHEM, 2012). By unmasking some of the mechanisms of patriarchy, the moral technology of the political regimen based on assumptions of gender hierarchy, we expose how it deepens inequalities and violates women's and girl's rights (DINIZ, 2014; HOOKS, 2015). With this lens, we discuss how Zika exposes the effects of this

political regimen of inequality and the role that such regimen has in placing women and girls in situations of everlasting vulnerability.

In this sense, this dissertation will also shed light on the effects of the criminalization of abortion in the context of Zika. Criminalization of abortion is one of the mechanisms of how patriarchy controls, and even out laws, women's and girls' bodies and health necessities. It is a central expression of how gender inequality shifts the political dialogue away from women, consequently leading to the violation of their rights. Zika's sexual and reproductive consequences exposed how the criminalization of abortion condemns social and political discourse about the Zika epidemic and its legacy. Abortion, not being a protected health need for women affected by the virus or at risk of infection, muted all further discussions; it destines women of reproductive age affected by Zika to a supposedly immutable fate. The absence of reproductive options enabled Zika to become much more than just a tropical, febrile, usually self-limited disease. It transformed Zika into a torment for Brazilian women and helped conceal the effects of the Zika epidemic and its legacy.

The first confirmed case of Zika infection in a human was reported more than ten years after the virus was first isolated from a sentinel monkey in the Zika forest in Uganda in 1947 (BAUD et al., 2017; DICK; KITCHEN; HADDOW, 1952; WIKAN; SMITH, 2016). Zika, a flavivirus, was not a cause for alarm until a large number of newborns in Brazil started to be diagnosed with head circumferences significantly below the expected standard deviations. Zika is thought to have spread throughout Asia and Africa, mostly undetected without causing any major outbreaks or epidemics for many decades and was mostly only known by tropical disease specialists (BAUD et al., 2017; WIKAN; SMITH, 2016). Before reaching Brazil, Zika caused a couple of recorded smaller outbreaks. The first one in the Yap Island in 2007, and a second one in French Polynesia in 2013-2014 (BAUD et al., 2017). Zika related symptoms of malaise, rash, and low-grade fever are not uncommon among populations that live in tropical areas and where other tropical diseases like dengue, malaria, and chikungunya are endemic.

Aedes aegypti, the main mosquito vector of the Zika virus, is present in all Brazilian regions, and it is also the main vector for the dengue virus (BRASIL, 2017a; AGÊNCIA FIOCRUZ DE NOTÍCIA, 2013). Although *Aedes aegypti* had been eliminated from the national territory in the 1950s, it is now thought as "practically impossible" to be eliminated given the disorderly urban growth and lack of adequate sanitary infrastructure (AGÊNCIA FIOCRUZ DE NOTÍCIA, 2013). Febrile, usually self-limited, mosquito-borne diseases are a part of life in the communities most affected by Zika (DINIZ, 2016). In fact, many affected women in Brazil initially described Zika infection manifestations as an "allergy" or "mild

dengue” (DINIZ, 2016; DINIZ; BRITO, 2016). There seemed to be no reason for alarm or to suspect that this illness would be any different. The reproductive health effects that Zika was found to cause created an international scare but had little to no change on sexual and reproductive health and rights or social protection policies (WENHAM et al., 2021).

The poorest regions of the country are the most affected. In 2016, the northeast region had the second highest incidence of Zika infection cases in the country (BRASIL, 2017b). This region also has the highest concentration of CZS cases (DE OLIVERIA et al., 2017; BRASIL, 2021a). Since monitoring by the Brazilian public health system began in late 2015, there have been 19,622 notified suspected CZS cases and 3,577 confirmed (BRASIL, 2021a). Almost 3,000 suspected CZS cases are still under investigation (BRASIL, 2021a). More than 20% of confirmed CZS are born to adolescent women, 19 years old or younger. (BRASIL, 2021a). Most deaths due to CZS happened in 2016 and are also concentrated in the northeast region (BRASIL, 2021a). Zika continues to be circulating in the country and there were reported cases up to 2020 (BRASIL, 2021a). Just in 2020, there were over 1,000 suspected cases with more than half (597) still under investigation, 35 were confirmed CZS cases and 46 were classified as probable CZS cases (BRASIL, 2021a). It is important to point out that since the early months of 2020, Brazil has been impacted by the COVID-19 pandemic (BRASIL, 2020a). The pandemic has placed the country among the three leading nations in the number of confirmed COVID-19 cases and second worldwide in the numbers of deaths due to SARS-CoV-2 infection (WORLD HEALTH ORGANIZATION, 2021a). This could have delayed or even obscured the true extent of the most recent epidemiological picture regarding Zika infections and CZS.

The Zika epidemic was a preventable public health event that exposed some of the preexisting conditions that allowed for the virus to flourish in Brazil and disproportionately impact women and girls. Although all of the reasons why the Zika epidemic was concentrated in Brazil might never be known, particularly in the northeast region, the analyses should not stop at human development indexes or geographical and climatic characteristics. Social and gender inequality are two fundamental factors that must be considered along with all the historical intersectional oppressions. Poverty, lack of infrastructure, basic sanitation, and information access are fundamental to understand why Zika has primarily affected people living in the poorest regions of the country. However, a critical analysis of social and economic inequalities is not sufficient if it does not explore how gender, race, migration status, and disability, among other factors, intersect compounding vulnerabilities. Moreover, given that the centrality of the threat of Zika is due to the consequences on women’s reproduction in a context

of extreme oppression of sexual and reproductive rights, gender inequality is fundamental to understanding Zika's legacy.

Brazil has one of the world's most restrictive abortion laws. According to the 1940 penal code, abortion is considered a crime, except if the pregnancy is due to rape or if there is no other way to save the woman's life (BRASIL, 1940). More recently, in 2012, the Brazilian Supreme Court ruled that the termination of pregnancy in cases of anencephalic fetuses is also permitted (BRASIL, 2012). Along with the criminalization of abortion comes some indicators of the alarming state of women's and girls' health in the country. Brazil has very high rates of maternal mortality, more than triple that of neighboring Uruguay, and six to seven times higher than countries in the Global North with national health systems, such as Canada, France, or the United Kingdom (THE WORLD BANK, 2019). The Brazilian northeast region has one of the highest rates of maternal mortality and abortion in the country (BRASIL, 2019a; BRASIL, 2009a; CARDOSO; VIEIRA; SARACENI, 2020; DINIZ; MEDEIROS; MADEIRO, 2017). Abortion remains among the five leading causes of maternal death (KASSEBAUM et al., 2016; WORLD HEALTH ORGANIZATION/PAHO, 2018; BRASIL, 2018; CARDOSO; VIEIRA; SARACENI, 2020). There are at least 250,000 hospitalizations a year due to unsafe abortions in the Brazilian public health system, SUS (Sistema Unico de Saúde) (DINIZ; MEDEIROS; MADEIRO, 2017; BRASIL, 2018; CARDOSO; VIEIRA; SARACENI, 2020). Every two days a woman dies as a consequence of unsafe abortion in Brazil (BRASIL, 2018). Yet, the Brazilian health notification systems does not contain or allow for the collection of any data specifically regarding unsafe abortions (CARDOSO; VIEIRA; SARACENI, 2020).

Uruguay demonstrated the indispensability of decriminalization of abortion along with the implementation of specific social policies to protect women's rights. As it happens, when a health need is guaranteed, Uruguay obtained a significant reduction in maternal mortality, predominately due to the decrease in unsafe abortion (BRIOZZO et al., 2016). Some other places around the world also report similar important reductions in maternal mortality rates following the legalization of abortion, such as Romania and South Africa (SINGH et al., 2017). A 30-year period analysis of global trends has shown that abortion rates declined in regions where abortion is legal, and increased where they are not (BEARAK et al., 2020). Unintended pregnancies were also higher in places where abortions are restricted (BEARAK et al., 2020). On December 30, 2020, Argentina, another bordering country, made a landmark decision to legalize abortion, upholding human rights and public health (ARGENTINA, 2020). This is an essential step to move towards gender equality in our region. These regional examples should be helpful to Brazil in establishing new and effective strategies to reach the agreed upon

Sustainable Development Goals for 2030 and significantly reduce maternal mortality (BRASIL, 2019b).

The northeast region of Brazil has high rates of violence against women and women living in this region are among the most social and economically vulnerable in the country (BRASIL, 2016b; POSENATO GARCIA et al., 2013; FÓRUM BRASILEIRO DE SEGURANÇA PÚBLICA, 2020). The north and northeast regions of Brazil also have the highest rates of infant mortality (BRASILa; LANSKY et al., 2014). More than half (55.4%) of the pregnancies in Brazil are unplanned (THEME-FILHA et al., 2016). Between 2015-2019, there were yearly 400,000 to 500,000 live births among girls 19 years old or younger in Brazil (BRASILb). The northeast region leads the charts despite never being the most populated region (BRASILb). Of these live births, an average of 20,000 a year were born to girls 14 or younger, most of these also concentrated in the northeast region (BRASILb). These pregnancies are a violation of human rights. Pregnancies in girls 15 or younger are associated with increased risk for adverse pregnancy outcomes and maternal death rates are almost 5 times higher in this age group than among older women (20-24yo) (CONDE-AGUDELO; BELIZÁN; LAMMERS, 2005). These girls have the right to abortion guaranteed by the Brazilian constitution given presumed rape if younger than 14 years old (BRASIL, 2009b) and given the risk of death (BRASIL, 1940). Yet, in the middle of the COVID-19 pandemic, a 10-year-old girl was denied an abortion in her state and had to hid in the trunk of car after flying 1,600km in order to be able to get the care she needed (GUIMARÃES, 2020). The protests and threats to her life were so violent that now she lives under a protection program (GUIMARÃES, 2020).

Only by exploring the multiple inequalities is it possible to better comprehend how they intersect to lead to such grave rights violation. As Flavia Rios and Márcia Lima summarizes when introducing Lélia Gonzalez's essay collection: "The situation of the amefrican women results from the historical and contemporary processes of intersectional oppression." (GONZALEZ, 2020, p. 21, our translation). Gonzalez coins the term "Amefricans" to relinquish hegemonic impositions and claim the singularity of black, Latin, and indigenous peoples' experience in America without forgoing the ties with Africa. It is a concept that goes beyond geography and carries the intersection of historical and social processes between these continents. It precedes slave trade and allows for the construction of the ethnic identity of a group who have historically lived under a racist system of power in America. (GONZALEZ, 2020, p 175-181). Gonzalez points out how natural racism is to the hegemonic power structures and alerts that Brazilian amefrican women will continue to be regarded as and studied in a way

that reproduces racist epistemology, unless these structures are challenged, and identities recreated (GONZALEZ, 2020, p 97-98).

The invisibility and omission of the black women in health issues and public policies are rooted in the double exclusion imposed on them for not being white nor male (CARNEIRO, 2011a; GONZALEZ, 2020; RIBERIO, 2020). Sueli Carneiro describes the intersecting of these oppressions as a double whammy that causes a “sort of social asphyxiation” of black women (CARNEIRO, 2011b, p.109, our translation). It forces black women into the most excluded and vulnerable social positions; black women fare worse than black men and white women (CARNEIRO, 2011a; REIBERIO, 2020). Racism is then found to be the main articulating axis in gender relations, as it determines gender hierarchy itself in our societies; otherwise, black women would fare at least as well as white women (CARNEIRO, 2011a). The inadequacy of universalizing public policies to deal with the intersection of these multiple inequalities that affect black Brazilian women becomes evident when reviewing sexual and reproductive health outcomes (CARNEIRO, 2003; CARNEIRO, 2011a; CARNEIRO, 2011b). Brazilian amefrican women¹ have been the target of public health policies for mass sterilization programs (CARNEIRO, 2003; CARNEIRO 2011b; VENTURA, 2009). The myth of racial democracy tries to erase race from public policies and public discourse; it has consequently led to the chronic omission of race/color data from health information, imposing an invisibility on black women (CARNEIRO, 2003; CARNEIRO, 2011a; CARNEIRO, 2011b, RIBERIO, 2020).

Reproductive justice is a concept that helps in the analysis of how the intersection of all these factors affects women’s reproductive lives. As a community-based movement founded by Black women in the United States, reproductive justice provides a framework that allows structural and institutional oppressions to be integrated into the analysis of human rights violations and claims (ROSS, 2017). It takes into account the historical, economic, and social aspects that affect women’s ability to fully exercise and achieve their human rights (ROSS, 2017). Reproductive justice integrates reproductive health and reproductive rights with social justice and challenges the focus placed solely on issues of access, choice, and the centrality of abortion (ROSS, 2006). It demands a broader analysis of the social injustices and other conditions that prevent women from achieving reproductive justice (ROSS, 2001). The right to have a child, the right not to have a child, the right to plan reproductive lives, and the right to parent and raise a child with dignity are seen as equally important (ROSS, 2006).

¹ The term Brazilian amefrican is used here as this policy targeted broadly poor women, composed of mostly black women (GONZALEZ, 2020; VENTURA, 2009).

One of the relevant applications of reproductive justice as Loretta Ross, one of the twelve founders of reproductive justice explained, is that “Reproductive justice is a process of synthesis with which to explore new territory and make new human rights claims” (ROSS, 2017, p. 306), and by “Using the concept of multiple lenses to express polyvocal standpoints, reproductive justice allows reframing of values and demands that multiple audiences perceive as vital and fundamental to their human rights” (ROSS, 2017, p. 303). It is an inclusive framework that allows for a feminist intersectional analysis of oppressions to go from theory to praxis. Although the amplexity of reproductive justice could be interpreted as a flaw of this framework, it is precisely this aspect that permits its plurality and constant reassessment. As Ross put it: “Reproductive justice thrives in the borderlands of ambiguity, and its incompleteness offers amazing flexibility and adaptability to allow multiple interpretations that invite elaboration and clarification” (ROSS, 2017, p. 306).

Reproductive justice provides an important framework to understand that the basis of the threat that Zika imposes on Brazilian women’s sexual and reproductive lives goes beyond the virus and its mosquito vector; it is structured on epistemological power dynamics that leave women and their communities destitute of basic necessities (ROSS, 2017). It allows for new human rights claims to be adequately established. The findings of most of the research presented here confirm what was presented by the petition to the Brazilian Supreme Court asking that the rights of women affected by or at risk of Zika be protected. This petition, the *Ação Direta de Inconstitucionalidade - ADI 5581/2016*, requested that women and children affected by Zika or at risk of Zika infection have guaranteed their right to: information regarding the virus and its consequences, sexual and reproductive health (SRH), including the right to abortion, access to treatment for children with CZS, and cash benefit transfers (BPC – *Benefício de prestação continuada*) for children with CZS (BRASIL, 2016a).

Although, this petition was later dismissed by the courts on technical grounds, it was an important precedent for women’s rights as it reframed discussions, opening the way for another Supreme Court petition arguing for the decriminalization of abortion, the *Arguição de Descumprimento de Preceito Fundamentada - ADPF 442/2017* (BRASIL, 2017d). In August 2018, the supreme court held a two-day public hearing regarding the decriminalization of abortion; a final ruling is still pending (BRASIL, 2018). This demonstrates the importance of the praxis of reproductive justice and evidence-based policies gathered through feminist research in establishing needed and urgent shifts in public discourse regarding abortion and sexual and reproductive health and rights in Brazil (WENHAM, 2021).

Reproductive justice also allows for a more comprehensive analysis of the Zika impact on vulnerabilities. Although the concept of vulnerability in research ethics, bioethics, and public health has received some important criticism, Florencia Luna provides a relevant insight into the idea that goes along with the premises of reproductive justice. Luna's approach to vulnerability as layers, not as labels, provides the necessary distance from the inflexible, taxonomic, generalizing, and categorizing subpopulations approach to vulnerability that can be stigmatizing and does not permit a more complex analysis. The idea of "layers of vulnerability" becomes an important instrument for the "understanding of how new vulnerabilities arise from conditions of economic, social, and political exclusion" (LUNA, 2009, p. 121), which is an essential understanding for a feminist perspective in bioethics.

Luna explains:

"Another way of understanding this proposal is not by thinking that someone *is* vulnerable, but by considering a particular situation that *makes or renders* someone vulnerable. If the situation changes, the person may no longer be considered vulnerable. A French working woman of reproductive age with middle- to-low income may not be vulnerable in a research protocol if she unwillingly gets pregnant (because in her country, if she wants to, she can get emergency contraception or an abortion at the public hospital), whereas if she is in Chile (where legal abortion is not allowed for any reason), that same French woman, in that same protocol, may acquire a layer of vulnerability. She does not become vulnerable, *simpliciter*. She acquires a layer of vulnerability; she is vulnerable in some particular aspect that is the result of the interaction of her particular circumstances and her own characteristics." (LUNA, 2009, p. 129, author's italics)

This comprehension regarding vulnerabilities allows for a more ample view of the contexts, as well as how vulnerabilities overlap and can lead to more vulnerabilities. Zika in Brazil showed a wide and variable range of situations that can render women vulnerable – from just being a woman or girl of reproductive age with unmet contraceptive needs, to experiencing mental suffering due to having had a Zika infection while pregnant and presented with the impossibility of getting a legal abortion, or being a young mother of five living in extreme poverty in a very remote area that lacks basic infrastructure with a child with CZS that cannot breathe or eat without some sort of medical intervention. Luna's feminist, non-idealist comprehension of people and their contexts allows for the layers of vulnerability approach to transcend the boundaries of the conceptual and be applicable on the practical level (LUNA, 2019). It allows for creativity and flexibility in the development of means that would adequately interfere in either blocking a trigger for a cascade of vulnerabilities, i.e. unintended pregnancy, or by creating ways to effectively change the contexts that render people vulnerable (LUNA, 2019). As such, this dynamic, contextual, and relational approach has also been instrumental in the analysis of the Zika impact on women's lives in Brazil.

Since the Zika epidemic in Brazil, several Ebola virus disease outbreaks have happened and another PHEIC due to COVID-19 has been declared (WORLD HEALTH ORGANIZATION, 2021b; WORLD HEALTH ORGANIZATION, 2020). Public health emergencies are concentrated in the Global South² and disproportionately affect women and girls (ANKER, 2007; SMITH, 2019; HARMAN, 2016; DAVIES; BENNETT, 2016; FARMER, 2005; RICHARDSON, 2020). Gender has been considered an important factor in determining health outcomes (HAWKES; BUSE, 2013; HEISE et al., 2019). However, a gender analysis is often omitted or overlooked in health policies and programs, and emergency responses consequently reinforce inequalities (DEBRUIN; LIASCHENKO; MARSHALL, 2012; HARRIS; SILVERMAN; MARSHALL, 2016; SMITH, 2019). Ebola epidemics have demonstrated a negative impact on SRH, with a decline in contraceptive use, family planning, and antenatal visits (BIETSCH; WILLIAMSON; REEVES, 2020; CAMARA et al., 2017).

As a consequence of disruptions due to the COVID-19 pandemic, the United Nations Population Fund (UNFPA) most optimistic estimation is that there will be between a 11.4%-14.5% increase in unmet need of modern contraception among women of reproductive age living in Latin America and the Caribbean region (LAC) (UNFPA, 2020). Brazil leads the contraceptive deficit in the region, concentrating more than two thirds of the shortage, according to UNFPA estimates (UNFPA, 2020). Along with that, the impact of COVID-19 on SRH in the LAC region has been estimated to cause a rise in adolescent pregnancy, thousands of maternal and neonatal deaths, 2.2 million unwanted pregnancies and more than one million abortions (UNFPA, 2020; ECLAC, 2020). Health crises had already demonstrated the urgent need to create emergency responses that are able to effectively protect women's and girls' rights (HARRIS; SILVERMAN; MARSHALL, 2016; DAVIES; BENNETT, 2016). Yet, the data regarding the global health reposes and estimated impact of COVID-19 continue to suggest that no sufficient change has taken place (SMITH, 2019; RILEY et al., 2020; GUTTMACHER INSTITUTE, 2020).

As a former colony and part of the Global South, Brazil's power structure has developed and is based on asymmetric relationships of gender, race, nationality, and class, where subordination to preestablished hierarchies remain central in the social fabric (ASSIS, 2014; REGO; PALÁCIOS, 2016). Coloniality, as Rego and Palacios explained, is "something that

² Global South as the concept described by Dados and Connell, 2012: "The term Global South functions as more than a metaphor for underdevelopment. It references an entire history of colonialism, neo-imperialism, and differential economic and social change through which large inequalities in living standards, life expectancy, and access to resources are maintained" (DADOS; CONNELL, 2012, p. 13).

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” (REGO; PALÁCIOS, 2016, p. 431). Lugones draws attention to the idea that by analyzing “the coloniality of gender” we are able “[...] to understand the oppressive imposition as a complex interaction of economic, racializing, and gendering systems in which every person in the colonial encounter can be found as a live, historical, fully described being” (LUGONES, 2014, p. 747). These concepts help construct the understanding of how gender inequality affects women and girls in Brazil and how Zika played a part in it.

The coloniality of capitalist patriarchy sets the stage for Zika to be the most hazardous to poor Afro-Brazilian young women and girls living in the areas that have suffered and continue to suffer the most from exploitative socioeconomic relations. The Zika legacy in Brazil, particularly among the lives of affected women, is much more than the occurrence of a tropical disease, it is the expression of gender inequality created by the coloniality of gender. It is the result of the intersection of a virus with “[...] the racial, political economic, social, epistemological, linguistic, and gendered hierarchical orders imposed by European colonialism [...]” (RICHARDSON, 2020, p. 73-74), and other institutional and structural forces such as racism and environmental racism (ROSS, 2017).

Public health has been described as a mechanism through which coloniality operates to maintain inequities by creating and applying its own epistemology (FARMER, 2005; RICHARDSON, 2020). In much of the same manner, patriarchy operates to oppress women and girls. It makes the questions and provides the solutions by framing the issue in a way to reinforce the hegemonic position. Patriarchy made Zika infection and its consequences an immutable fate for poor women and girls in Brazil, just as pregnancy and motherhood have always been. Abortion was not permitted under the patriarchal structures of power. This political regimen deconstructed any formal, constitutionally-guaranteed right by disappearing with the need. Since the beginning of the epidemic, the health authority response to Zika has been focused on combatting the mosquito vector (WORLD HEALTH ORGANIZATION, 2016b; BRASIL, 2017c), effectively removing women and girls of reproductive age and SRH, including abortion, from the picture. This is how the patriarchal system operates and how it managed the Zika epidemic (HEISE et al., 2019). As such, the racist colonial capitalist patriarchal system of power created a “truth”³ about the Zika legacy in which abortion, contraception, and women’s and girls’ rights were not a part of it. The most consequential

³ The regimen of truth described by Foucault’s *Microphysics of Power* as being produced by and intrinsically linked to the systems of power (FOUCAULT, 1979).

aspect of Zika virus infection – its effects on sexual and reproductive health and rights – was then eliminated from the discussion, as were the main effects of the Zika epidemic.

This dissertation exposes that not placing sexual and reproductive health and rights as a central aspect of public health emergency responses allowed the Zika outbreak to be utilized as an apparatus of the patriarchal system to perpetuate gender and social inequalities. This analysis is presented in the following three articles and an editorial piece. This format for the elaboration of this dissertation was chosen for a few reasons: it allows for more timely presentation of the findings and for a more ample dissemination of the research among peers; articles allow for the division of the research into parts that can be more accessible to a larger and more diverse group of people; it is a small step towards the democratization of the information, as articles can be more easily translated into fact sheets, key messages, summary points, even social media cards/bits.

In the first section, the published article presented describes how Zika has worsened social and economic vulnerabilities of the women affected in the state with the lowest Human Development Index in Brazil, Alagoas. As they live the Zika legacy, the young women and their families live an imposed nonexistence. Social protections policies did not adequately reach them; very little reached them, reifying the immutability of Zika effects as imposed by the patriarchal order. It provides evidence to the essentiality of social justice for the praxis of reproductive justice. The following section, an unpublished article, focuses on the sexual and reproductive health and rights of these women and exposes how inadequate and insufficient SRH access and information compounds the existing social and economic vulnerabilities. As such, it reveals the gendered quality of inequalities. It exposed the importance of reproductive health within reproductive justice and exposes how the silence around SRH governs women's and girls' lives. Next, there is an unpublished article that explores how power dynamics permit the exploitation of the vulnerabilities of affected women and children as research participants. It provides evidence of how common mechanisms for research ethics, designed by the Global North, fails to protect women in vulnerable situations in the context of research during a public health emergency. Following, there is a brief published editorial on how medical paternalism, as intended by the hegemonic structures of power, created a seamless path for unethical research practices that exploited women's vulnerabilities and violated their right to autonomy.

Altogether, these articles analyze several facets of gender asymmetry in the context of a public health emergency. Zika has only caused devastating consequences where sexual and reproductive rights of women and girls are not being guaranteed. As a dissertation based on feminist research, it exposes how the political regimen imposed by gender governs and

negatively impacts the lives of women and girls – it made them a casualty of the Zika epidemic. By breaking with the hierarchical assumptions of gender, it displays the mechanism through which patriarchy erased the sexual and reproductive needs of women, and along with it, the Zika effects from the political agenda. The bioethical importance of this work comes from the urgent need to reframe reproductive rights issues and gender equality as a public health priority. This shift in framing public health emergencies is essential for the development of ethical interventions in the face of social and gender inequalities (DINIZ; GUILHEM; 2012).

Zika's singularity of being a public health emergency due to reproductive consequences allowed it to be an unequivocal case study of the effects of public health emergencies on sexual and reproductive health and rights of women living in the Global South. It adds evidence to the importance of placing women and girls at the center of any public health emergency response and that a diverse and flexible approach is needed to protect rights and prevent vulnerabilities. The purpose of this study is to expose the impact caused by the Zika epidemic on the lives of those most affected by it – black Brazilian, amefrican, young women and girls living in vulnerable situations. This study demonstrates that in academic discussions, production of scientific information, and public policies formulation, feminist lenses are a fundamental way to expose the often occult effects of gender inequality and reproductive injustices. The hope is to create new and adequate ways to guarantee gender equality, reproductive justice, and rights of women and girls during public health crises by comprehending the essentiality of a feminist perspective when formulating responses to them.

2 RESEARCH ARTICLES

2.1 The vulnerabilities of lives: Zika, women and children in Alagoas State, Brazil

Ilana G. Ambrogi¹

Luciana Brito²

Debora Diniz^{3 4}

¹ Programa de Pós-graduação em Bioética Ética Aplicada e Saúde Coletiva, Fundação Oswaldo Cruz, Rio de Janeiro, Brasil.

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

³ International Planned Parenthood Federation, London, U.K.

⁴ Universidade de Brasília, Brasília, Brasil.

Correspondência

I. G. Ambrogi Programa de Pós-graduação em Bioética, Ética Aplicada e Saúde Coletiva, Escola Nacional de Saúde Pública Sergio Arouca, Fundação Oswaldo Cruz. Rua Leopoldo Bulhões 1480, Rio de Janeiro, RJ 21041-210. ilanaambrogi@gmail.com

Contribuição

All authors contributed equally in this manuscript. ORCID: Ilana G. Ambrogi (0000-0003-2886-4284); Luciana Brito (0000-0001-8752-2386); Debora Diniz (0000-0001-6987-2569).

This article was published on Cadernos de Saúde Pública, Reports in Public Health v 36 n°.12, Rio de Janeiro, Dezembro 2020 ISSN 1678-4464. <http://dx.doi.org/10.1590/0102-311X00032020>

Article presented according with the journal's format requirements.

As vulnerabilidades das vidas: Zika, mulheres e crianças no Estado de Alagoas, Brasil

Ilana G. Ambrogi, Luciana Brito, Debora Diniz

<http://dx.doi.org/10.1590/0102-311X00032020>

RESUMO

Até 2015, o Zika vírus era praticamente desconhecido no Brasil e no mundo. Desde então, descobriu-se que o vírus é transmitido verticalmente, da gestante para o feto, e que causa a síndrome congênita do Zika vírus (SCZV). O estudo tem como objetivo descrever e analisar as vulnerabilidades das mulheres e crianças mais afetadas pela epidemia do Zika no Brasil. Alagoas é o estado do Brasil com o Índice de Desenvolvimento Humano mais baixo, e com uma das maiores taxas de gravidez na adolescência. Entre dezembro de 2016 e março de 2017, foram realizadas entrevistas com 54 mulheres com crianças afetadas pelo Zika. As entrevistas tinham dois componentes: uma conversa orientada por narrativa e um questionário semiestruturado. Este estudo de casos com métodos mistos representa 45% dos casos confirmados de SCZV e 20% dos casos investigados no estado na época. As mulheres eram predominantemente afro-brasileiras, a maioria primigesta durante a adolescência e com baixa escolaridade. Muitas não estavam inscritas em programas de proteção social e não recebiam cuidados de saúde adequados. Os direitos e necessidades dessas mulheres e crianças são impactados pela falta sistemática de acesso a serviços e medicamentos. Há deficiências no transporte público até os serviços de saúde, dos quais dependem muitas famílias. A discriminação contra os filhos com a síndrome é um conceito novo e complexo na vida dessas mulheres. A epidemia do Zika agravou as violações de seus direitos e os fatores sociais e econômicos de sua vulnerabilidade. Há uma necessidade urgente de uma resposta pública

robusta para garantir os direitos dessas mulheres e crianças e para implementar mecanismos para prevenir e eliminar as vulnerabilidades.

Zika Virus; Direitos Humanos; Iniquidade Social; Direitos da Mulher; Populações Vulneráveis

ABSTRACT

Until 2015, Zika was mostly unknown in Brazil and in the world. Since then, the Zika virus has been found to be vertically transmitted and to cause congenital Zika syndrome (CZS). This study aims to describe and analyze the vulnerabilities of the women and children most affected by the Zika epidemic in Brazil. Alagoas has the lowest Human Development Index in Brazil and one of the highest rates of adolescent pregnancy. Between December 2016 and March 2017, interviews were conducted with 54 women with children affected by Zika. The interviews had two components: a narrative-oriented conversation and a semi-structured questionnaire. This comprehensive mixed methods case study represented 45% of the confirmed CZS cases and 20% of the cases under investigation in the state at that time. The women are predominantly Afro-Brazilian; most experienced their first pregnancy during adolescence, and had little education. Many were not covered by social protection programs and were not receiving adequate health care. The rights and needs of these women and children are impacted by a systemic lack of access to services and medications. There is inadequate transportation to services that many families depend on. Discrimination against their children with disabilities is a new and complex concept in their lives. The Zika epidemic has compounded rights violations in their lives and worsened their social and economic layers of vulnerability. There is an urgent need for a robust public response to guarantee the rights of these women and children and to implement mechanisms to prevent and eliminate their vulnerabilities.

Zika Virus; Human Rights; Social Inequity; Women's Rights; Vulnerable Populations

INTRODUCTION

In February 2016, the World Health Organization (WHO) declared a global emergency situation due to the effects of Zika virus infection during pregnancy. In Brazil, the Northeast Region was the epicenter of the country's epidemic. Given Zika's effects on embryonic, fetal, and postnatal development, the virus became a concern for women of reproductive age and

particularly for those who were pregnant at the time ^{1,2}. During this epidemic, the northeastern states of Bahia and Pernambuco were considered to have the highest incidence of cases ³. Alagoas, a small state nested between Bahia and Pernambuco and with the lowest HDI (Human Development Index) in the country ⁴, was considered a “paradox” by the Ministry of Health authorities given its low number of reported cases during the epidemic ⁵. Alagoas has similar climatic, geographical, social and economic characteristics to the heavily affected states. The claim of an unexpectedly low number of reported cases of Zika in Alagoas should raise many questions.

Currently, Brazil continues to be the global epicenter of Zika illness. There are still cases of congenital Zika syndrome (CZS) and of Zika viral illness being reported. From the onset of monitoring of the epidemic in November 2015 through December 2019, there were more than 280,000 reported cases of people with suspected Zika illness ^{6,7,8} and 18,578 reported cases of newborns suspected of having CZS ⁹. Of these newborns, 3,496 were subsequently confirmed as having the syndrome, 763 were classified as probable syndrome cases, 2,665 still remained under investigation and 638 were considered inconclusive ⁹. Nationally, according to the latest epidemiological report that reported on this, only 35% of the children with CZS are receiving early stimulation services ¹⁰ and 39% are not getting any specialized care ¹¹. Moreover, 37% of children with the diagnosis are not even receiving routine pediatric/primary care ¹¹. The majority of these children - 2,189 of them - are concentrated in the Northeast region, which is also the region that has the highest number of reported fetal, neonatal and infant deaths suspected to be related to Zika infection ^{9,11}.

By December 2016, at the time this field research was conducted, the Ministry of Health announced that Alagoas had 371 reported cases of newborns suspected of having CZS, which represented 3.6% of the national total for that year. Of the total reported cases in Alagoas, 86 were confirmed to be CZS, 51 cases were still under investigation and 234 cases were ultimately discarded ¹². Calculations using the epidemiological data available at the end of 2016 showed that Alagoas had twice as many discarded cases of newborns suspected for CZS per 10,000 live births as its neighboring state, Bahia. Alagoas had 22/10,000 live births as discarded cases while Bahia had half of that: 11/10,000. From the start of the epidemic in 2015 through the end in December 2016, 76% of all the reported suspected cases in Alagoas were either discarded or were still awaiting a final diagnosis ⁵.

The clinical criteria used for epidemiological surveillance during the public health alert were newborns with signs of microcephaly as determined by head circumference measurements.

These criteria not only changed during the epidemic, due to attempts to establish an international standardization, but they were also hard to implement^{13,14}. In addition to the complexity of the situation, federal and state governments developed different response policies for identifying suspected cases^{15,16}. The expectation that fetal alterations would be identified by prenatal ultrasound also does not account for the realities of regional and local public health services. Public health services only guarantee one ultrasound during pregnancy, which is usually done in the early stages of pregnancy, a period when the effects of Zika are not usually detectable^{17,18,19}.

In its first protocol for epidemiological surveillance of microcephaly due to Zika virus infection published by the Alagoas State Department of Health, a non-contrast computerized tomography (CT) of the head was required for newborns with microcephaly suspected to be due to Zika. This differed from the national protocol, where a transfontale ultrasound not only was an alternative to the head CT but was also considered to be the preferred method, given the exposure to radiation in the CT exam and the frequent need for sedation. Although Alagoas has since updated its protocol to include transfontale ultrasound as a possible imaging option, the protocol still states that head CT is the preferred method, since it is more readily available in the state than ultrasound^{15,16}. Alagoas has only two public hospitals with tomography machines and the wait time for an exam is several months²⁰.

All of these obstacles to access care and to obtain a diagnosis and treatment have a significant compound effect on the preexisting vulnerabilities of the most affected population²¹. In this study, vulnerability is understood according to a practical sphere; it is relational, dynamic and context-dependent. Vulnerabilities can be multiple and distinct. They can be layered and potentiate further vulnerabilities and human rights violations. Each preexisting vulnerability can increase the chances for another, and this can have a cascade and cumulative effect²¹. The analysis of layers of vulnerability must include the social context and, in the case of women and children affected by Zika, it should consider previously identified aspects of their lives. Social, economic and gender inequalities place people in situations that enhance the layers of vulnerabilities, particularly when living in places that have been historically ruled by oppressive patriarchal systems and that are underdeveloped.

In order to minimize and/or eradicate vulnerabilities, it is important to study and determine which situations can trigger the cascade layers of vulnerability²¹. The life circumstances of those most affected by Zika remain unchanged, there continues to be new cases of CZS reported⁸ and the recent political change in Brazil has significantly impacted the chances of

this population obtaining health care and other resources necessary for their well-being. This study aims to describe and analyze the layers of vulnerabilities of the women and children most affected by the Zika epidemic in Alagoas. It shows how the aftermath of the Zika epidemic not only intensified many of their social and economic vulnerabilities but also how the outbreak triggered a cascade effect that reaffirms the potential of epidemics to become “poverty traps” for those affected ²².

METHODS

This was a comprehensive mixed methods case study conducted in the Brazilian state of Alagoas. This study is part of a larger research project and some of its findings were discussed in the report *Zika in Brazil - Women and Children at the Center of the Epidemic*⁵. During December 2016, our research team traveled over 800 kilometers and visited 21 municipalities in the state. Data collection was finalized in March 2017. Active search for families occurred via different sources: official epidemiological surveillance records (municipal, state, and federal), WhatsApp (a popular mobile communication application) groups of mothers and caregivers of children with CZS, health teams at reference centers, and community contacts. Official state records did not provide names for the women affected, only the names of the municipalities where the cases were recorded. Using this information, the research team traveled to the municipalities - most of which are remote and sparsely populated. Public transport was also scarce, and motorcycles were commonly used as taxi transportation. Upon arriving in the municipalities, the researchers asked drivers at these motorcycle taxi stops whether they knew of any affected children.

The data in this article reflect the biomedical literature available at the time of the unfolding epidemic. There have since been several changes in parameters and guidelines as more information became known ^{13,15}. Interviews were conducted with 54 women with children who had confirmed or suspected CZS according to the criteria at the time of their birth or during pediatric care. The interviews were individual, most at the women's homes. Four women were interviewed on the day of their children's consultation at the Dr. Helvio Auto University Hospital - the state's reference center for treatment of tropical diseases.

The interviews had two methodological components. The first was a narrative-oriented conversation, with a topic guide that explored demographic elements, access to social benefits (income transfer, medications and transportation), as well as infant care and experiences of discrimination. The second methodological component was a semi-structured questionnaire that repeated some questions from the narrative-oriented conversation with emphasis on

demographic elements (age, ethnicity, income, number of children, education), urbanization and housing (sewage, garbage collection, type of housing), and access to health services and early stimulation for the child. Each interview lasted approximately 60 minutes. One third of the women were interviewed more than once for adequate data collection. After transcribing the interviews, some answers were clarified or confirmed over the phone. Data analysis was based on thematic analysis, enabling the preparation of a conceptual description²³. Data were coded and grouped by concepts for the formulation of themes of what emerged from the data, without being previously conceived²⁴.

Of the 54 female participants, 39 had a child with confirmed CZS, 10 had a child who was still under investigation for Zika effects and other congenital infections, and 5 were excluded from the analyses due to notification errors. This sample represents 45% of the confirmed cases of CZS and 20% of the cases under investigation in Alagoas at the end of December 2016. Of the total number of municipalities with confirmed cases (40), this study covered 52% (n = 21). After initially disaggregating the data of the 2 groups of women by age, ethnicity, level of education, access to social benefits, there were no significant differences between the 2 groups of women interviewed. Consequently, the data on women with children with a confirmed diagnosis and those with children whose cases were still under investigation were combined for the analysis presented here.

The exclusion criteria were as follows: if the newborn had diagnostic imaging with a normal result; if full-term newborn head circumference was 33cm at birth (the cutoff for microcephaly in 2016 was 32cm, lowered from 33cm in 2015)¹³; if the women did not have any record or recollection of Zika illness during pregnancy; if the child had not shown any symptoms or signs of developmental delay or neurological disorder according to pediatric records; and if there was diagnostic confirmation by more than one medical professional that this was not a case of CZS.

Ten children without definitive diagnosis were included in the analysis because they fell into at least one of the following 3 inclusion categories: they did not meet the Brazilian Ministry of Health criteria to be considered a discarded case; they were classified as having a congenital syndrome other than Zika but imaging was suggestive of congenital infection that did not match the suspected diagnosis; children born in Alagoas in late 2015 or during 2016 who presented with multiple signs and symptoms that required similar if not identical living and care needs as children with CZS.

Additional data on reported cases of CZS in Alagoas were collected from the Brazilian Ministry of Health and from the Brazilian Ministry of Social and Agrarian Development. This data collection complied with the Law of Access to Information (LAI) - *Law n. 12,527/2011*, which regulates the right to obtain access to public information. Available data on all cases reported in the state between 2015 and April 2017 were requested. These data contained disaggregated information on the women's ethnicity, age, place of residence, and social assistance for their children. These data were cross-referenced with the data we collected in the interviews and analyzed as presented in the results section.

This study was funded by the Wellcome Trust and DFID, 206021/Z/16/Z. Prior to the start of any field activities, the research protocol was reviewed and approved by the University of Brasilia Research Ethics committee for humanities and social science - CAAE: 63604016.4.0000.5540. This study complied with the International Ethical Guidelines for Health-related Research Involving Humans. Oral Informed consent was preferred given the low levels of literacy among the study participants and the low risk level of the research intervention. In order to ensure immediate benefit sharing, at the end of each interview the families were informed about the social benefits available for their specific needs. The team also answered participants' questions related to access to child health, sexual and reproductive care, or social welfare assistance and provided information regarding available services when appropriate. Considering the importance of benefit sharing at the time of the research intervention, this ethical approach was enabled by the presence of a social worker, a lawyer, a physician, a nurse and a community health agent in the research team.

RESULTS AND DISCUSSION

Participants' profile

The participants' age ranged from 14 to 43 years. However, only 3 women were past their twenties. About half of the women, 51% ($n = 25$), became pregnant and were affected by the epidemic during their adolescence. Adolescent mothers were aged 14 to 19 years. Six of the women became pregnant before their 15th birthday. Taking into account previous children, 75% ($n = 37$) of the women interviewed had first become pregnant during adolescence. According to data from the Brazilian National Information System on Live Births (SINASC), this number is about three times higher than the state's adolescent pregnancy rate (26%), which is already among the highest in the country, and around four times the national rate (18%) (<http://tabnet.datasus.gov.br/cgi/defthtm.exe?sinasc/cnv/nval.def>, accessed on 18/Feb/2020).

In addition to being very young, most women were Afro-Brazilian (80%, n = 39), which is higher than the state's racial distribution of Afro-Brazilian persons (72%) and much higher than the national ratio (53%)²⁵. As for the level of formal education, young age seemed to compound these women's vulnerabilities. Three of the women (6%) were illiterate, which is higher than the national incidence of illiteracy and thus suggests the level of precariousness of their lives. According to the *Brazilian National Household Sample Survey* (PNAD), the national illiteracy rate is 1.4% for women in a comparable age range - 24 to 29 years²⁵. Again, lower than expected levels of education. For almost half of the adolescents, the level of formal education was very low: 52% (n = 13) had not completed elementary school. The national rate of adolescents aged 17 to 19 years with incomplete elementary education is less than 15%²⁵. Generally, their education is disrupted because of poverty and/or early pregnancy and the failure of social welfare policies.

Income and lack of access to social welfare programs

The analysis of income information took into consideration that there is often resistance in disclosing incomes due to both fear and embarrassment. The fear is that the information may be possibly misused or misrepresented, thereby risking the loss of social benefits, which are allotted based on income. Questions related to income in contexts of extreme poverty can also provoke shame and timidity. However, despite these limitations, the different sources of data confirmed that the participants were living in extremely vulnerable socio-economic conditions. Yet, despite their poverty, several families did not receive the Bolsa Família benefit, one of the main social welfare programs for poor families in Brazil.

There are two major social welfare programs in place for these families: Brazilian Income Transfer Program (*Bolsa Família*) and the Continuous Cash Benefit (*Benefício de Prestação Continuada* - BPC). Brazilian Income Transfer Program is an income transfer program for very poor families with children younger than 17 years at home²⁶. BPC is a Brazilian income transfer benefit equivalent to a minimum wage paid monthly to every person with a disability whose family income per capita is less than ¼ of the monthly minimum wage salary (i.e. USD 50 per person/month)²⁷. Despite the many vulnerabilities of their lives and having children with disabilities, most families in the study did not receive the BPC (63%, n = 31). The women described significant barriers to obtaining this benefit to which they were entitled. First, the medical and social service documents that are required to register for the benefit program were considered to be excessive and cumbersome to obtain. The women also frequently mentioned

the lack of transportation as an insuperable barrier to completing the required bureaucratic process.

As for the Brazilian Income Transfer Program, there were primarily two, interrelated, reasons for the low number of families registered for the program, despite most of them meeting its criteria. First, women reported that the local social security officers informed families that they were not allowed to receive the two benefits (BPC and Brazilian Income Transfer Program) for the same child/family; second, families did not want to risk losing the BPC, which provides a larger amount of money than Brazilian Income Transfer Program, by trying to also obtain the Brazilian Income Transfer Program. The reality of how these benefits are understood and in fact granted differ from the actual criteria as established by law. These benefits are not mutually exclusive and the Brazilian Income Transfer Program income amount is not supposed to be used in calculations of household per capita income when determining eligibility for BPC^{27,28}. The Brazilian Income Transfer Program is a benefit thought for the entire family which usually includes other children, while the BPC is an assistance for the unmet financial needs of a specific individual.

Of the 25 adolescent mothers with a child confirmed or under investigation for CZS, 40% (n = 10) were not participating in any income transfer programs: neither BPC nor Brazilian Income Transfer Program. When the programs were analyzed separately, it was found that 76% (n = 19) of the adolescent mothers did not receive BPC for their eligible child and 44% (n = 11) did not receive Brazilian Income Transfer Program even though they were entitled to both. The highest inequity of benefits allotted were among adolescent mothers with children with CZS. Only 1 in 4 of those entitled to participate in an income transfer program was registered.

It is at the intersection between the different requirements of the different programs that the adolescent women's vulnerabilities become more acute: out of school, they are not eligible for Bolsa Familia for their household because the criterion of inclusion for the program is school enrollment; adolescent mothers without record of civil emancipation were not understood as subject of rights for their children with CZS. The alternative for some adolescents was to register the child as a dependent of their grandparents, despite living in different homes.

More than half of the women had been engaged in paid work before their pregnancy (53%, n = 26), and 76% of them had not returned to work after childbirth. Their jobs were in agriculture, retail, education or as housemaids. All families, to different degrees, reported experiencing a decrease in their standard of living and an increase in expenses after their child's birth, including

with transportation and health care. In this sense, BPC is decisive for the survival of these families and the guarantee of care for the children. The requirement of an extremely low level of income for families to access the benefit has significant consequences on the families' well-being and access to fundamental rights. It caused women to feel trapped and conflicted about returning to paid work.

Need for transportation to services

In most municipalities visited, there was no public transportation to either of the two state's reference centers for pediatric early stimulation therapy, which are located in the cities of Maceió and Arapiraca. Over half of the women (55%, $n = 27$) depended entirely on transportation provided by their municipality, such as ambulances or chartered cars, to take their infant to weekly 30-minute physical therapy/occupational therapy/early stimulation sessions. Of the remaining women, 45% ($n = 22$) reported that given the lack of transportation services provided by the municipality, they were unable to take their children to the prescribed early stimulation sessions as recommended by the health care professionals. On average, round-trip commute to services was 3 hours. The families with the shortest commute were those who lived closest to the reference centers. The more remote families traveled up to 6 hours round-trip for the 30-minute early stimulation therapy session.

Many remote municipalities of Alagoas have scarce or, in many cases, nonexistent public transportation. This study showed that half of these children depend on the local municipal government for transportation in order to get to the needed services. In addition, there were abundant reports of transportation involving safety issues and mistreatment. There is a crucial need for outreach to remote, low-income areas where many of the participants live. As mandated by Brazilian law, these families are entitled to reliable and safe transportation for themselves and/or for providers to be able to visit their homes. Home visits or mobile medical vehicles with a multidisciplinary team should be considered for families affected by Zika and others with similar, multiple vulnerabilities ²⁹.

Need for medications and supplies

Despite the Brazilian legislation recognizing health as a right of its citizens and a government's responsibility, of the 23 children (47%) on daily prescribed medication, only 6 received medication from public health services. There was a systemic lack of medications, in particular anti-epileptic drugs, in public health services and pharmacies. About half of the families, 53% ($n = 13$) who were prescribed medications to control seizures reported not having the financial means to buy the medication without some sort of assistance. There have been cases of children

who experienced uncontrolled seizures and had to be hospitalized for prolonged periods of time because of complications such as aspiration pneumonia. At the time of data collection, none of the women interviewed whose child had a need for visual aid had received eyeglasses via the public health system. The participants also reported recurrent issues of inadequate staffing and/or shortage of supplies in the local health care facilities. These reports echo the findings of the most recent official epidemiological report, which showed that over 35% of the children with confirmed CZS are not getting specialized care and/or even routine pediatric care ¹¹.

Discrimination and the meaning of having a “special child”

None of the women interviewed described their child as having a disability or even a disease or syndrome. Rather, the women described the child who needed extra care at home and more medical attention as a “special child”. During the interviews, the word “disability” was never used as an emic category to describe the “special child”. Disability was still a category used primarily among academic and activist movements in Brazil. It did not possess an emic significance for these women. Nor did Zika or CZS. The women have instead embraced microcephaly as the term that describes the physical condition of the child who needs specialized care.

When asked “What does he have that makes him have to go to the doctor?”, the primary answer was “He has microcephaly”. To comprehend the significance of the word “microcephaly” to these women, it is necessary to consider the layers of meanings that emerge in their accounts. The first was the normalization of the child, because microcephaly was simply intended to mean “a small head”. It was common to hear “He is normal, he only has the microcephaly problem”, which could falsely suggest a misunderstanding about the meaning of the medical diagnosis. “Normal” and microcephaly was a pair that needed to be joined to confront public curiosity about the child with the “mosquito problem”. Describing the child as normal is a way of rejecting the degrading and offensive questions that nearly all of the women had heard at some point, either when the child was born or upon their return home. Women were asked whether they were going to abandon their child, be able to love the child, or thought of the child as beautiful.

Occurrences that could be described as public expressions of discrimination were commonly described by the women as acts merely based on “curiosity”. People removing hats from babies' heads or touching them were rarely described with a language that implicates rights violations or denounces the discrimination suffered. There is a subtle layer here of cultural language and accommodation to humiliation: not all curiosity was understood as offensive, because life

experiences in the community are considered to be shared experiences. To identify the curiosity of others as a form of discrimination was not an instinctual or immediate process for many women, yet as the child grows the pairing of microcephaly with “normal” becomes increasingly more difficult. It is a complex affective and moral construct about maternity, inclusion, care and struggles against discrimination.

FINAL CONSIDERATIONS

This study describes the impacts of the Zika epidemic on the lives of women and children in Alagoas. The arrival of Zika in Brazil triggered and intensified vulnerabilities that were already part of these women's lives, due to inequalities that have long existed in Brazil. In order to minimize the negative effects of Zika, there is an urgent need for public policies to safeguard the rights of the women and children at the center of the epidemic and those who remain at most risk³⁰. A Supreme Court case requesting the protection of rights of women and children affected by Zika filed in 2016 had its hearing scheduled, after a four-year wait, suddenly during the COVID-19 pandemic in April 2020. The court dismissed the case on procedural grounds³¹. In a time span of four years, these children and women are now living a second public health crisis, the COVID-19 pandemic, and many of their fundamental needs remain unmet¹¹.

The social and economic vulnerabilities that put women and children at risk for Zika remain. The growing children have developed different medical, social and educational needs. Children of school age need individualized educational plans as well as transport and accessibility to public spaces³². The higher number of discarded cases observed in Alagoas during the aforementioned period should lead to the consideration that there might be children still in need of further evaluation. The reasons that led the Brazilian Northeast region to be the epicenter of the Zika epidemic are not fully known³³ - what is known, however, is that the epidemic revealed structural fragility in public policies that should have protected the most vulnerable. Rights violations were observed in several domains of the lives of women and children participants: from lack of adequate medical care and late diagnosis of the syndrome in newborns to discrimination and harassment.

Women are the principal caregivers³⁴ and are on the frontlines of the daily struggles. Loss of income has been observed in these families and the BPC, the cash transfer benefit, is considered an important financial aid^{34,35}. In March 2020, after the Federal Senate's reversal of a presidential veto, a law proposal from 1996 requesting the raise of the minimum per capita income to qualify for this cash transfer benefit so more families could be included was finally approved³⁶. This triggered an immediate reaction from the executive branch of the government

leading to an appeal to the Supreme Court for the law to be barred. The court sided with the government and suspended the new law and the proposed changes for BPC qualification never actually went into effect³⁷. Throughout the years, it is not uncommon for individual families caring for affected children to appeal to the courts requesting cash transfer benefit, the BPC, by demonstrating that their expenditures greatly surpass their family income. However, this is usually a long, difficult and bureaucratic process that adds yet another layer to their situation of vulnerability^{38,39}.

Zika not only exposed various rights violations that have been systematically disregarded but also showed how those violations exacerbate the vulnerabilities of these women and children⁴⁰. Even though our data was limited by purposive sampling, Brazil continues to be the global epicenter of Zika illness. The virus and the vector are still present in the country. New cases continue to be reported⁹. In order to prevent the worsening of their living situation, we must first determine the vulnerabilities among these women and children. This study does that. It is a first step toward minimizing, preventing and even eradicating the most harmful layers of vulnerability that put this population at risk for Zika and its negative effects. Public and social health policies must attend to the needs of women and children already affected by Zika and of those at risk. It is urgent that authorities engage in both more research and action.

Acknowledgments

We acknowledge all research participants for their time. We would also like to express our gratitude to the Wellcome Trust and the DFID (206021/Z/16/Z) for the funding of this study. The funders of this study had no participation in study design, data collection and analysis, data interpretation, writing or editing of this report. We declare no conflicts of interest.

REFERENCES

1. Moore CA, Staples JE, Dobyys WB, Pessoa A, Ventura CV, Fonseca EB, et al. Characterizing the pattern of anomalies in congenital Zika syndrome for pediatric clinicians. *JAMA Pediatr* 2017; 171:288-95.
2. Martines RB, Bhatnagar J, de Oliveira Ramos AM, Davi HPF, Iglezias SD'A, Kanamura TK, et al. Pathology of congenital Zika syndrome in Brazil: a case series. *Lancet* 2016; 388:898-904.
3. Secretaria de Vigilância em Saúde, Ministério da Saúde. Vírus Zika no Brasil: a resposta do SUS. Brasília: Ministério da Saúde; 2017.

4. Instituto de Pesquisa Econômica Aplicada. Desenvolvimento humano nas macrorregiões brasileiras.
http://www.ipea.gov.br/portal/images/stories/PDFs/livros/livros/20160331_livro-idhm.pdf
(accessed on 18/Feb/2020).
5. Diniz D. Zika in Brazil: women and children at the center of the epidemic. Brasília: Letras Livres; 2017.
6. Secretaria de Vigilância em Saúde, Ministério da Saúde. Monitoramento dos casos de dengue, febre de chikungunya e doença aguda pelo vírus Zika até a Semana Epidemiológica 52 de 2018. Boletim Epidemiológico 2018; 50(04).
<http://portalarquivos2.saude.gov.br/images/pdf/2019/janeiro/28/2019-002.pdf>.
7. Secretaria de Vigilância em Saúde, Ministério da Saúde. Situação epidemiológica da infecção pelo vírus Zika no Brasil, de 2015 a 2017. Boletim Epidemiológico 2018; 49(47).
<http://portalarquivos2.saude.gov.br/images/pdf/2018/novembro/12/2018-034.pdf>.
8. Secretaria de Vigilância em Saúde, Ministério da Saúde. Monitoramento dos casos de arboviroses urbanas transmitidas pelo Aedes (dengue, chikungunya e Zika), Semanas epidemiológicas 01 a 52. Boletim Epidemiológico 2020; 51(02).
<https://portalarquivos2.saude.gov.br/images/pdf/2020/janeiro/20/Boletim-epidemiologico-SVS-02-1-.pdf>.
9. Secretaria de Vigilância em Saúde, Ministério da Saúde. Monitoramento dos casos de arboviroses urbanas transmitidas pelo Aedes (dengue, chikungunya e Zika), Semanas epidemiológicas 01 a 03. Boletim Epidemiológico 2020; 51(05).
<https://portalarquivos2.saude.gov.br/images/pdf/2020/fevereiro/05/Boletim-epidemiologico-SVS-05.pdf>.
10. Secretaria de Vigilância em Saúde, Ministério da Saúde. Monitoramento integrado de alterações no crescimento e desenvolvimento relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas, até a Semana Epidemiológica 52 de 2018. Boletim Epidemiológico 2019; 50(08).
<https://portalarquivos2.saude.gov.br/images/pdf/2019/marco/22/2019-001.pdf>.
11. Secretaria de Vigilância em Saúde, Ministério da Saúde. Síndrome congênita associada à infecção pelo vírus Zika: situação epidemiológica, ações desenvolvidas e desafios, 2015 a 2019. Boletim Epidemiológico 2019; 50(n.esp).
<https://portalarquivos2.saude.gov.br/images/pdf/2019/dezembro/05/be-sindrome-congenita-vfinal.pdf>.

12. Secretaria de Vigilância em Saúde, Ministério da Saúde. Monitoramento integrado de alterações no crescimento e desenvolvimentgo relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas, da Semana Epidemiológica 45/2015 até a Semana Epidemiológica 02/2017. Boletim Epidemiológico 2017; 48(06). http://portalarquivos.saude.gov.br/images/pdf/2017/fevereiro/27/2017_003.pdf.
13. Ministério da Saúde. Brasil adota recomendação da OMS e reduz medida para microcefalia. 2016. <http://www.saude.gov.br/noticias/agencia-saude/22553-brasil-adota-recomendacao-da-oms-e-reduz-medida-para-microcefalia> (accessed on 18/Feb/2020).
14. Ashwal S, Michelson D, Plawner L, Dobyns WB. Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society. Practice parameter: evaluation of the child with microcephaly (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society. *Neurology* 2009; 359:887-97.
15. Secretaria de Estado da Saúde de Alagoas. Protocolo integrado para vigilância, atenção à saúde e prevenção da síndrome congênita relacionada à Infecção pelo Zika Vírus em Alagoas. <http://www.saude.al.gov.br/wp-content/uploads/2018/05/Protocolo-integrado-SCZ-2018.pdf> (accessed on 18/Feb/2020).
16. Ministério da Saúde. Orientações integradas de vigilância e atenção à saúde no âmbito da emergência de saúde pública de importância nacional: procedimentos para o monitoramento das alterações no crescimento e desenvolvimento a partir da gestação até a primeira infância, relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas dentro da capacidade operacional do SUS (versão 1.0). <http://portalarquivos.saude.gov.br/images/pdf/2016/dezembro/12/orientacoes-integradas-vigilancia-atencao.pdf> (accessed on 18/Feb/2020).
17. Ministério da Saúde. Portaria nº 650, de 5 de Outubro de 2011. Diário Oficial da União 2011; 6 oct.
18. Eppes C, Rac M, Dunn J, Versalovic J, Murray KO, Suter MA, et al. Testing for Zika virus infection in pregnancy: key concepts to deal with an emerging epidemic. *Am J Obstet Gynecol* 2017; 216:209-25.
19. Van der Linden V, Pessoa A, Dobyns W, Barkovich AJ, van der Linden Júnior H, Rolim Filho EL, et al. Description of 13 infants born during October 2015-January 2016 with congenital Zika virus infection without microcephaly at birth - Brazil. *MMWR Morb Mortal Wkly Rep* 2016; 65:1343-8.

20. Secretaria da Saúde de Alagoas. Guia de serviços. Tomografia sem contraste. <https://www.servicos.al.gov.br/servico/59cbf1968c36c71c557215ac/exame-de-tomografia-sem-contraste/> (accessed on 17/Feb/2020).
21. Luna F. Identifying and evaluating layers of vulnerability - a way forward. *Dev World Bioeth* 2019; 19:86-95.
22. Masanjala WH. HIV/AIDS, Household income, and consumption dynamics in Malawi. In: Gillespie S, editors. *AIDS, poverty, and hunger: challenges and responses. Highlights of the International Conference on HIV/ AIDS and Food and Nutrition Security, Durban, South Africa, 14-16, 2005.* Washington DC: International Food Policy Research Institute; 2006. p. 58.
23. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3:77-101.
24. Corbin JM, Strauss AL. *Basics of qualitative research: techniques and procedures for developing grounded theory.* Los Angeles: Sage Publications; 2008.
25. Instituto Brasileiro de Geografia e Estatística. *Pesquisa Nacional por Amostra de Domicílios: síntese de indicadores 2015.* Rio de Janeiro: Instituto Brasileiro de Geografia e Estatística; 2016.
26. Secretaria Especial do Desenvolvimento Social. *Bolsa Família. Como funciona.* <http://mds.gov.br/assuntos/bolsa-familia/o-que-e/como-funciona/como-funciona> (accessed on 17/Dec/2019).
27. Brasil. Lei nº 8.742, 7 de dezembro de 1993. Dispõe sobre a organização da Assistência Social e dá outras providências. *Diário Oficial da União* 1993; 8 dec.
28. Brasil. Lei nº 10.836, 9 de Janeiro de 2004. Cria o Programa Bolsa Família e dá outras providências. *Diário Oficial da União* 2004; 12 jan.
29. Norr KF, Crittenden KS, Lehrer EL, Reyes O, Boyd CB, Nacion KW, et al. Maternal and infant outcomes at one year for a nurse-health advocate home visiting program serving African Americans and Mexican Americans. *Public Health Nurs* 2003; 20:190-203.
30. Santos BMC, Coelho FC, Armstrong M, Saraceni V, Lemos C. Zika: an ongoing threat to women and infants. *Cad Saúde Pública* 2018; 34:e00038218.
31. Supremo Tribunal Federal. Ação Direta de Inconstitucionalidade n. 5581, 04 de maio de 2020. <http://portal.stf.jus.br/processos/detalhe.asp?incidente=5037704> (accessed on 12/May/2020).

32. Sá MRC, Vieira ACD, Castro BSM, Agostini O, Smythe T, Kuper H, et al. De toda maneira tem que andar junto: ações intersetoriais entre saúde e educação para crianças vivendo com a síndrome congênita do vírus Zika. *Cad Saúde Pública* 2019; 35:e00233718.
33. Oliveira WK, França GVA, Carmo EH, Duncan BB, Souza Kuchenbecker R, Schmidt MI. Infection-related microcephaly after the 2015 and 2016 Zika virus outbreaks in Brazil: a surveillance-based analysis. *Lancet* 2017; 390:861-70.
34. Sá SAAG, Galindo CC, Dantas RS, Moura JC. Dinâmica familiar de criança com a síndrome congênita do Zika vírus no Município de Petrolina, Pernambuco, Brasil. *Cad Saúde Pública* 2020; 36:e00246518.
35. Freitas PSS, Soares GB, Mocelin HJS, Lacerda LCX, Prado TN, Sales CMM, et al. Síndrome congênita do vírus Zika: perfil sociodemográfico das mães. *Rev Panam Salud Pública* 2018; 43:e24.
36. Brasil. Lei nº 13.981, de 23 de março de 2020. Altera a Lei nº 8.742, de 7 de dezembro de 1993 (Lei Orgânica da Assistência Social). *Diário Oficial da União* 2020; 24 mar.
37. Supremo Tribunal Federal. Arguição de Descumprimento de Preceito Fundamental (ADPF) 662, 03 Abril 2020. <http://portal.stf.jus.br/processos/detalhe.asp?incidente=5880970> (accessed on 12/May/2020).
38. Matos SS, Quadros MT, Silva ACR. A negociação do acesso ao Benefício de Prestação Continuada por crianças com síndrome congênita do Zika vírus em Pernambuco. *Anuário Antropológico* 2019; (II):229-60.
39. Pereira EL, Bezerra JC, Brant JL, Araújo WN, Santos LMP. Perfil da demanda e dos Benefícios de Prestação Continuada (BPC) concedidos a crianças com diagnóstico de microcefalia no Brasil. *Ciênc Saúde Colet* 2017; 22:3557-66
40. Barbeito-Andrés J, Pezzuto P, Higa LM, Dias AA, Vasconcelos JM, Santos TMP, et al. Congenital Zika syndrome is associated with maternal protein malnutrition. *Sci Adv* 2020; 6:eaaw6284.

This is an open-access article distributed under the terms of the Creative Commons Attribution License.

2.2 Zika Public Health Emergency in Brazil: Women and Sexual and Reproductive Health needs

Ilana G. Ambrogi^{1 2}

Luciana Brito²

Debora Diniz^{3 4}

¹ Programa de Pós-graduação em Bioética Ética Aplicada e Saúde Coletiva, Fundação Oswaldo Cruz, Rio de Janeiro, Brasil.

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

³ Deputy Director, International Planned Parenthood Federation, Western Hemisphere, New York, NY, USA

⁴ Universidade de Brasília, Brasília, Brasil.

At the time this dissertation was finalized, this article is in process for submission.

Abstract:**Background:**

The brunt of the Zika epidemic's impact has been concentrated among the poorest and most vulnerable women in Brazil. This study in the northeastern state of Alagoas focused specifically on unmet sexual and reproductive health needs among women affected by the Zika epidemic. Alagoas has the lowest Human Development Index in Brazil and one of the highest rates of adolescent pregnancy.

Methods:

Between December 2016 and March 2017, a mixed-methods study was conducted with 54 women with Zika-affected children. The women were from 21 different municipalities and represented 45% of the state's confirmed cases of congenital Zika syndrome (CZS) and 20% of the cases still under investigation.

Findings:

The majority of women were Afro-Brazilian, had little education, and had had a first pregnancy when they were still adolescents. About half of the women were not currently using any method to avoid pregnancy, although none expressed any plans to have another child. Among those women who did use contraceptives, the pill was the most common method, but adherence was irregular. Hormonal injection was the second most commonly used method. Only one woman used an IUD. The study also found that being affected by Zika had negative effects on the women's mental health.

Interpretation:

The study results confirm that the Zika public health emergency in a population with inadequate sexual and reproductive health not only leaves women in endangered situations but also deepens their vulnerabilities. Safeguarding sexual and reproductive health is fundamental in public health emergencies.

Keywords: Zika virus, Women, Brazil, Public Health Emergency, Sexual and Reproductive Health

Introduction:

Brazil, more specifically its Northeast region, was the epicenter of the Zika epidemic from late 2015 through 2016.^{1,2} Before then, the Zika virus had been unknown in this part of the world and the virus's negative effects on pregnancy and fetal and post-natal development had been unknown to science.³ The increase in neurological disorders and neonatal malformations in areas temporally associated with Zika infection led the World Health Organization (WHO) to declare a Public Health Emergency of International Concern (PHEIC) in February 2016.⁴ The WHO declaration was lifted later that same year and the Brazilian government followed suit in May 2017 by declaring the end of its national public health emergency.^{5,6} However, while the numbers of reported Zika cases as well as suspected cases of congenital Zika syndrome (CZS) have decreased since the outbreak, the Brazilian Northeast continues to be the epicenter for the consequences of Zika infection.^{7,8} Those children affected by Zika require specialized care and continue to live in a state of extreme social vulnerability.^{9,10}

The northeastern state of Alagoas has the lowest Human Development Index (HDI) in the country and the highest rate of adolescent pregnancy.^{11,12} The same region also has very high rates of violence against women^{13,14}, maternal mortality^{15,16}, and unsafe abortions^{17,18}. The risk factors for unintended pregnancies in Brazil are similar to those in other settings in Latin America and the Caribbean, as well as the United States: socioeconomic inequalities, young age, and lack of social supports.¹⁹⁻²¹ Approximately 55.4% of pregnancies in Brazil are unintended, a number that is likely underestimated given that, at least in the most recent national study, women were only asked about their pregnancy intention after they had given birth, during their early postpartum period.²¹ Despite reported high contraceptive use rates among Brazilian women, there is still significant unmet need for contraceptives in the Northeast.^{22,23}

Rates of unintended pregnancy in Brazil are higher among young and adolescent Brazilian women with declared black, brown or yellow skin color/race, with low levels of schooling, women with no partners, women without paid work, and women who are dependent on social welfare programs.^{21,24} Unintended pregnancies in turn are more likely to end in abortions.^{25,26} Yet abortion is considered a crime in Brazil, except in cases of rape, an anencephalic fetus, or risk to the woman's life.^{27,28} Despite restrictive abortion laws in Brazil, one in five women in Brazil has had at least one illegal abortion by the age of 40.¹⁷ Every year, almost 500,000 women in Brazil undergo clandestine abortions.¹⁷ Unsafe abortion puts women at risk of death and increased morbidity.^{26,29} The combination of unmet contraceptive needs, high rates of

adolescent pregnancy, and unintended pregnancies create significant risks for women who are already underserved and vulnerable.

The Brazilian Ministry of Health's information efforts regarding Zika prevention is generally limited to protective measures against mosquito transmission. On the Ministry's official website, there is no section that specifically addresses women of reproductive age – there is only a single line stating that if women do not want to get pregnant, they should seek out contraceptives. There are brief references to “safe sex” without any explanations as to what that entails. There is no mention of condoms.³⁰ The section for health providers is not much different. National information campaigns, now substantially reduced, are similarly limited in their scope, focusing primarily on vector prevention and symptoms for diagnosis. However, the population continues to be at risk for Zika and its consequences and those women most at risk do not have the means to adequately plan their reproductive lives.³¹ In the last few years since the epidemic was declared to be over, between 2018 and 2020, there were over 25,000 suspected cases of Zika in Brazil.^{32,33,34} From the beginning of the monitoring by the Brazilian public health system started in late 2015 there have been 19,622 notified suspected cases of CZS.⁷ More recently, in 2020, there were over 1,000 suspected cases with more than half (597) still under investigation, 35 were confirmed CZS cases and 46 were classified as probable CZS cases.⁷

When Zika arrived in the Northeast, it was a sudden, novel illness that brought unforeseen consequences, in particular for women of reproductive age. In Brazil, there are 3,577 cases of children with confirmed CZS and almost 3,000 cases still under investigation. More than 20% of confirmed CZS are born to adolescent women, 19 years old or younger.⁷ Most of these cases are concentrated in the Northeast, the poorest region in the country.⁷ The full impact of Zika on the lives and wellbeing of the women affected might never be fully known. Yet, these women continue to live with the threat of a new epidemic and the consequences of the previous one.^{7,31} This article aims to describe how a public health emergency in contexts of poverty both worsens women's vulnerabilities and deepens their unmet sexual and reproductive health needs.

Methods:

A comprehensive mixed-methods case study was conducted in the Brazilian state of Alagoas from December 2016 to March 2017. The methods included quantitative analysis of available epidemiological records and qualitative investigation in the form of in-depth interviews. The Zika

virus epidemic in Brazil peaked in 2016.¹ During the month of December 2016, our research team travelled throughout the state of Alagoas – covering over 800 kilometers and 21 municipalities. This study is part of a larger research project and some of its findings were discussed in the report *Zika in Brazil – Women and Children at the Center of the Epidemic*.³⁵ The active search for affected women occurred via different sources: official epidemiological surveillance records (municipal, state, and federal), *WhatsApp* (a phone communication application widely used in Brazil, including among affected women) groups of mothers and caregivers of children with CZS, health teams at reference centers, and community contacts.

Official state records did not provide any confidential or private information about the women or their affected children, only the names of the municipalities where cases were recorded. With only this geographical data in hand, the research team travelled to the municipalities, where they reached out to gatekeepers – community contacts such as healthcare personnel. If those gatekeepers knew of women with children "with the mosquito problem" – expression the local communities used to describe children affected by Zika virus – we would ask the gatekeepers to contact those women and ask whether they would be interested in speaking with the research team. The team only contacted women who responded yes.

We conducted interviews with 54 women with children who were confirmed or suspected to be cases of CZS based on criteria at the time of their birth or during their pediatric care. Interviews were performed individually, most of them at the women's homes. Only four interviews were conducted at Dr. Helvio Auto University Hospital – the state's reference center for treatment of tropical diseases, on the day of the child's consultation.

Interviews had two methodological components: a narrative-oriented conversation and a semi-structured questionnaire. Using topic guides, the researchers explored elements of reproductive and sexual health such as planning for future pregnancies, pregnancy intention for a current or past pregnancy, contraceptive methods – including access, availability, and utilization – childbirth, infant and postpartum care, access to information about Zika and sexual and reproductive health, Zika as a sexually transmitted infection, as well as experiences of personal distress and discrimination. The questionnaire repeated some questions from the open interview with emphasis on demographic elements such as age, ethnicity, income, access to social benefits, number of children, education, age during first pregnancy, housing situation, sewage availability, garbage collection, and access to health services and early stimulation services for the child. Each initial interview lasted approximately 60 minutes.

Data analysis was based on grounded theory and thematic analysis.^{36,37} Three researchers analyzed the collected data using microanalysis to generate code categories. The coding process was divided into two phases: open coding and axial coding.^{36,37} Provisional categories were developed through the process of constant comparison during the open coding phase of line-by-line examination. In axial coding, the analysis was focused on emerging categories, identifying central themes, and exploring their interrelationships. Memos were also used to define codes. The coding process was systematically discussed among the researchers and the principal investigator. After completing the initial analysis, we conducted additional shorter phone interviews with some of the participants to verify and complement any missing information.

Of the 54 women participants, 39 had a child with confirmed CZS, 10 had a child who was still undergoing investigation for Zika and other congenital infections, and 5 were excluded from the analyses due to notification errors. The participants represented 45% of the confirmed cases and 20% of the cases under investigation in Alagoas at the end of December 2016. Of the total number of municipalities with confirmed cases ($n = 40$), this study covered 52% ($n = 21$). After initially disaggregating the data for the two groups of women – those whose children were confirmed as having CZS and those whose children were still under investigation for CZS – by age, ethnicity, education, access to social assistance, and income, we found that there were no significant differences in the characteristics of the two groups. Consequently, the data from these groups are presented together here.

Inclusion criteria for women participants were those with:

- Children with a definitive official CZS diagnosis;
- Children who did not fulfill the Ministry of Health criteria to be excluded from the official surveillance protocol;
- Children who had laboratory results positive for a TORCH infection other than Zika but with patterns on head CT images consistent with CZS;
- Children born in Alagoas in late 2015 or during 2016 and who presented with multiple signs and symptoms that required similar if not identical living and care needs as children with confirmed CZS.

Exclusion criteria were as follows:

- Children with diagnostic imaging without any concerning changes;

- Children with head circumference measuring 33cm at birth (cutoff for microcephaly in 2016 was 32cm, lowered from 33cm in 2015);
- Women who did not have any record or recollection of Zika illness during pregnancy;
- Children who had not shown any signs or symptoms of developmental delay or neurological disorder according to pediatric records;
- Diagnostic confirmation by more than one medical professional that the child did not have CZS.

One ethical concern during the study was to seek to promote gender justice through benefit sharing, as it is understood as a human right.^{38,39} Providing or facilitating access to appropriate information as well as social assistance during the research process can enhance women's agency and promote equity.³⁹ At the end of each interview, women were informed about their rights, particularly regarding available social welfare benefits. The research team also provided answers and clarifications to the women's questions related to child health, sexual and reproductive health, or access to social welfare benefits. When appropriate, the team provided referrals to relevant services. Information about the research study, Zika, health, and rights was also provided in printed form with pictures, photos, and visual aids that were appropriate for the women's specific needs. The presence of a social worker, a lawyer, a physician, a nurse, and a community health agent on the research team allowed for this ethical approach. Accounting for gender-based inequities when benefit sharing is essential to ending gender-based inequities – these are important steps towards the protection of women's rights, particularly in low or middle-income countries, where gender-based disadvantages disproportionately impact women.³⁹

Prior to the onset of any activities, the research protocol was reviewed and approved by the University of Brasilia Research Ethics committee - CAAE: 63604016.4.0000.5540. The study was performed in accordance with the International Ethical Guidelines for Health-related Research Involving Humans. In cases when there might be possible reports of what could be considered a crime, there is no assurance of legal protection of confidentiality for research in Brazil, but there is strong moral vigilance in regard to reproductive practices, including the criminalization of abortion. Consequently, in those cases with more sensitive narratives, we chose to obtain only oral consent without any identifiers to serve as an additional protective layer of confidentiality.

Results and Discussion

Profile of participants

Participants ranged in age from 14 to 43 years old. Twenty-five (53%) of the participants were adolescents and only three were past their twenties. Thirty-nine (80%) of the participants identified as Afro-Brazilian. In Brazil and in Alagoas, the racial distribution of Afro-Brazilian is 53% and 72%, respectively.²⁶ There was also an overrepresentation of illiteracy among the women and low level of education among the adolescents. Three (6%) of the participants were illiterate – nationally, the illiteracy rate is only 1.4%.²⁶ Half of the adolescents (13) had not completed elementary school. Nationally, only 15% of adolescents 17 - 19 years old have not completed this level of education.⁴⁰ All participants fully depended on the public health system for care.

Precariousness of prenatal care and unmet need for reproductive health

Sixteen women (32%) had had a late start with prenatal care; that is, they only began prenatal care after the first trimester. One woman did not receive any prenatal care during her pregnancy. A previous study in the state's largest city had found that only 34% of pregnant women who used public health services had their first prenatal care visit before the 12th week of gestation.⁴¹ Only about 55% of pregnant women in the Northeast of Brazil received what is considered adequate prenatal care, that is, care beginning in the first trimester and including at least 6 total prenatal visits before birth.⁴² Thus, the percentage of women in the study who had a late start to prenatal care reflects the obstacles to reproductive care that already existed prior to the Zika epidemic.

The reasons for the late start to prenatal care are not fully known. One possibility for the delay may be the lack of adequate staffing and maintenance of health care facilities. The municipalities visited for this study are remote, and health care facilities, when available, are not structured to provide care for high-risk pregnancies. A recent large national Brazilian study found that 33% of pregnant women in the Northeast had to go to at least two hospitals before finding where they could have their delivery.⁴² Another possible explanation for delayed care is that women may not have known they were pregnant until they started experiencing physical signs. The participants described a “growing belly” as the first sign that they thought they might be pregnant, and many noted that they were still having menstrual periods up to when the pregnancy was confirmed by lab results or ultrasound.

Almost half of the women (43%, n = 21) were not using any contraceptive methods to avoid a new pregnancy, although none of them indicated current plans to have another child. Twenty-

eight (57%) of them reported that they had been using some contraceptive method when they found out about the pregnancy with their affected child. Among those who were currently using some method, the pill was the most common method (70%, n=19), but adherence was irregular. The second most commonly used method was injectable hormonal contraceptives (n=4). Only one woman used an IUD. Those women who did not use any contraceptive method were not able to state with certainty at the time of the interview whether or not they were pregnant.

None of the women were aware that Zika virus could be sexually transmitted. There was a widespread lack of knowledge or rejection of information about the risk of sexual transmission. The main counter-evidence was testimonial – as one participant explained, for example: “*In my house, I had Zika and my husband did not have it.*” The transformation of Zika from a mosquito-borne disease to a sexually transmitted disease requires a reconfiguration of the dominant narratives in the community as well as the way the topic is discussed in public policies.

Most of the participants were adolescents when they had their first child. Taking into account previous children, three in four women (n=37) had become pregnant during adolescence, which is higher than the state and national rates for adolescent pregnancy: 26% and 18%, respectively.¹¹ Six of them had first become pregnant before the age of 15. Twenty-five of the participants were adolescents or had been adolescents during the pregnancy affected by Zika virus. Among the adolescents, about half of them (n=13) were not using any birth control method at the time of the interview and none reported wanting another child. None of the adolescents used condoms or IUDs.

Lack of access to contraceptive methods further worsens the vulnerabilities of the adolescent women as exemplified by one participant’s statement: “*Currently, I am not using any method to avoid [a new pregnancy]. I was using the injection, but they ran out here at the [public] health clinic. But I am going to ask if they have the pill. I don’t want another child. I don’t.*” This assertion came from a 19-year-old woman who had recently given birth to a child whose case was under investigation for CZS. Another woman, a single mother of eight young children, the youngest of which had CZS, got pregnant while “waiting for a bilateral tubal ligation.” The precariousness of her life has been aggravated not only by Zika but also by its intersection with her unmet reproductive health needs.

Overall, the population of women reflected in this study have significant unmet sexual and reproductive health needs. Understanding those unmet needs is essential to understanding the full

consequences of the Zika virus on these women's lives. Another study with women in the Northeast also found a prevailing lack of pregnancy intention coupled with very low rates of usage of modern contraceptive methods.³¹ Unmet sexual and reproductive health needs further endanger the health and lives of Zika-affected women – an already vulnerable population.

The high number of unintended and adolescent pregnancies raises concerns as it indicates significant unmet sexual and reproductive health needs among adolescents. The inability to plan and control their reproductive lives have dire consequences for women, in particular in regions of the globe where abortion is criminalized.²⁹ Inadequate prenatal care increases the chances of negative outcomes for both women and children.⁴² Moreover, the pressures women face, from trying to manage their sexual and reproductive health to caring for a child with significant health demands, have serious mental health effects for many women.

Women shared how the impact of Zika in their lives had also affected their mental health. An 18-year-old participant reflected on the comments she receives in her community about her child: *'one day I took the bus. A woman looked at me and asked, "Is he a mosquito baby?" That hurt me a lot.'* The expressions "*children with the mosquito problem*" or "*small-headed children*" are part of narratives of stigma and the accommodation of communities to CZS as a new disease.

During the interview process, the research team's psychologist referred ten participants to mental health care services due to concerns for their mental health. One of the women asked specifically for psychological assistance. Two adolescents reported having thoughts about suicide and one of them reported getting close to an attempt. All the women who required specialized care were referred to counselling or health care services in their own municipalities.

Many of the Zika-affected children were not receiving adequate care and follow-up services,⁴³ nor are the health experts capable of fully addressing the uncertainty regarding the futures of these children and the full extent of Zika's effects on their development. Another domain of women's lives that was affected by Zika was livelihood: even though half of the women were engaged in paid work prior to their Zika-affected pregnancy (n=26), less than one fourth had returned to work since. Zika seems to have exponentially increased the vulnerability of these women's lives. There are many other life domains that were impacted by Zika infection and its consequences that are not discussed in this paper. Mental suffering, however, was observed as one of the more salient negative consequences.

Final considerations

Several public health emergencies have shown how sexual and reproductive health is a core public health issue.⁴⁴ The recent Zika epidemic in Brazil is yet one more example of how leaving a population with inadequate sexual and reproductive health can have far-reaching, devastating consequences. The chronic state of unmet sexual and reproductive health needs that preceded the arrival of the Zika virus in the Northeast of Brazil was a significant contributor to women's vulnerabilities to the effects of Zika infection, and the overall reach of the epidemic.

As reflected in the study's findings, the Zika public health emergency has had the most profound impacts on the most vulnerable populations. Although our study is limited by its purposive sampling, it provides compelling evidence of how the Zika epidemic has deepened the precariousness of women's lives. It is not a new concept that humanitarian emergencies further debilitate the health of those affected. Although sexual and reproductive health are not usually prioritized in crisis situations, they are fundamental human rights and essential for survival and rights protection.⁴⁵ The Zika epidemic public health emergency in Brazil had a direct consequence on sexual and reproductive health and revealed the fundamental role sexual and reproductive health and rights have on the lives of individuals as well as communities.

Contributors

All authors participated in all phases of the study, interpreted the data, critically revised the manuscript, approved the final version, and agreed to be accountable for all aspects of the work.

Declaration of interests

We declare no competing interests. The findings and conclusions in this report are those of the authors. The funding source of this study had no participation in study design, data collection and analysis, data interpretation, writing or editing of this report.

Acknowledgments

We thank all the research participants for their time. We would also like to express our gratitude to Wellcome Trust and DFID (206021/Z/16/Z) for funding the study.

References

1. DE OLIVEIRA, W. K. et al. Infection-related microcephaly after the 2015 and 2016 Zika virus outbreaks in Brazil: a surveillance-based analysis. **The Lancet**, v. 390, n. 10097, p. 861–870, 2017.
2. BRADY, O. J. et al. The association between Zika virus infection and microcephaly in Brazil 2015–2017: An observational analysis of over 4 million births. **PLoS medicine**, v. 16, n. 3, p. e1002755, 2019.
3. MARTINES, R. B. et al. Pathology of congenital Zika syndrome in Brazil: a case series. **The Lancet**, v. 388, n. 10047, p. 898–904, 2016.
4. WORLD HEALTH ORGANIZATION. **WHO statement on the first meeting of the International Health Regulations (2005) (IHR 2005) Emergency Committee on Zika virus and observed increase in neurological disorders and neonatal malformations**. 1 Feb 2016. Available at [https://www.who.int/news-room/detail/01-02-2016-who-statement-on-the-first-meeting-of-the-international-health-regulations-\(2005\)-\(ihr-2005\)-emergency-committee-on-zika-virus-and-observed-increase-in-neurological-disorders-and-neonatal-malformations](https://www.who.int/news-room/detail/01-02-2016-who-statement-on-the-first-meeting-of-the-international-health-regulations-(2005)-(ihr-2005)-emergency-committee-on-zika-virus-and-observed-increase-in-neurological-disorders-and-neonatal-malformations). Accessed: 24 Feb. 2021.
5. WORLD HEALTH ORGANIZATION. **Fifth meeting of the Emergency Committee under the International Health Regulations (2005) regarding microcephaly, other neurological disorders and Zika virus**. 18 Nov 2016. Available at: [https://www.who.int/news-room/detail/18-11-2016-fifth-meeting-of-the-emergency-committee-under-the-international-health-regulations-\(2005\)-regarding-microcephaly-other-neurological-disorders-and-zika-virus](https://www.who.int/news-room/detail/18-11-2016-fifth-meeting-of-the-emergency-committee-under-the-international-health-regulations-(2005)-regarding-microcephaly-other-neurological-disorders-and-zika-virus). Accessed 5 Mar. 2020.
6. BRASIL. Ministério da Saúde. **Ministério da Saúde declara fim da Emergência Nacional para Zika e microcefalia**. 11 May 2017. Available at: <https://www.gov.br/saude/pt-br/assuntos/noticias/ministerio-da-saude-declara-fim-da-emergencia-nacional-para-zika-e-microcefalia>. Accessed 6 Mar. 2021.
7. BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. **Boletim Epidemiológico: Situação epidemiológica da síndrome congênita associada à infecção pelo vírus Zika, 2015 a 2020**. N 04. Vol 52; 2021. Available at: https://www.gov.br/saude/pt-br/media/pdf/2021/fevereiro/11/boletim_epidemiologico_svs_4.pdf. Accessed: 25 Feb. 2021
8. WORLD HEALTH ORGANIZATION/PAHO. **Zika cases and congenital syndrome associated with Zika virus reported by countries and territories in the Americas, 2015 - 2018. Cumulative cases**. 04 January 2018. Available at: https://www.paho.org/hq/index.php?option=com_docman&view=download&category_slug=cumulative-cases-pdf-8865&alias=43296-zika-cumulative-cases-4-january-2018-296&Itemid=270&lang=en. Accessed: 5 Mar. 2021.
9. WENHAM, C. et al. Gender mainstreaming as a pathway for sustainable arbovirus control in Latin America. **PLoS Neglected Tropical Diseases**, v. 14, n. 2, p. 1–7, 2020.

10. AMBROGI, I. G.; BRITO, L.; DINIZ, D. The vulnerabilities of lives: Zika, women and children in Alagoas State, Brazil. **Cadernos de saude publica**, v. 36, n. 12, p. e00032020, 2021.
11. Brasil. Ministério da Saúde. **Secretaria de Vigilância em Saúde. Sistema de Informações sobre Nascidos Vivos – SINASC**. Available at: <http://tabnet.datasus.gov.br/cgi/defptohtm.exe?sinasc/cnv/nvuf.def>. Accessed 6 Mar. 2021.
12. BRASIL. IPEA. **Desenvolvimento Humano Nas Macrorregiões Brasileiras**. 2016b. Available at: http://www.ipea.gov.br/portal/images/stories/PDFs/livros/livros/20160331_livro-idhm.pdf. Accessed: 25 Feb. 2021.
13. POSENATO GARCIA, L. et al. **Violência contra a mulher: feminicídios no Brasil**. Instituto de Pesquisa Econômica Aplicada – Ipea, 2013. Available at: https://www.ipea.gov.br/portal/images/stories/PDFs/130925_sum_estudo_femicidio_leilagarcia.pdf Accessed: 25 Feb. 2021.
14. FÓRUM BRASILEIRO DE SEGURANÇA PÚBLICA. **Anuário Brasileiro de Segurança Pública 2020**. São Paulo: Ano 14 2020. ISSN 1983-7364. Available at: <https://forumseguranca.org.br/wp-content/uploads/2020/10/anuario-14-2020-v1-interativo.pdf>. Accessed: 25 Feb. 2021.
15. BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. **Manual dos comitês de mortalidade materna**. – 3. ed. – Brasília: Editora do Ministério da Saúde, 2009a. 104. Available at: http://bvsmis.saude.gov.br/bvs/publicacoes/manual_comites_mortalidade_materna.pdf. Accessed: 25 Feb. 2021.
16. BRASIL. Ministério da Saúde. **Departamento de Informática do SUS (DATASUS)**. Óbitos maternos por ano do óbito segundo região: período: 1996-2019. 2019a. Available at: <http://tabnet.datasus.gov.br/cgi/tabcgi.exe?sim/cnv/mat10uf.def>. Accessed: 25 Feb. 2021.
17. DINIZ, D.; MEDEIROS, M.; MADEIRO, A. Pesquisa Nacional de Aborto 2016. **Ciência & Saúde Coletiva**, v. 22, n. 2, p. 653–660, fev. 2017.
18. CARDOSO, B. B.; VIEIRA, F. M. DOS S. B.; SARACENI, V. Aborto no Brasil: o que dizem os dados oficiais? **Cadernos de Saúde Pública**, v. 36, n. suppl 1, p. 1–13, 2020.
19. FINER, L. B.; ZOLNA, M. R. Unintended pregnancy in the United States: incidence and disparities, 2006. **Contraception**, v. 84, n. 5, p. 478–485, Nov. 2011.
20. SULLY, E. A.; BIDDLECOM, A. S.; DARROCH, J. E. Not all inequalities are equal: Differences in coverage across the continuum of reproductive health services. **BMJ Global Health**, v. 4, n. 5, p. 7–11, 2019.

21. THEME-FILHA, M. M. et al. Factors associated with unintended pregnancy in Brazil: cross-sectional results from the Birth in Brazil National Survey, 2011/2012. **Reproductive Health**, v. 13, n. S3, p. 118, 17 Oct. 2016.
22. BRASIL. Ministério da Saúde. Centro Brasileiro de Análise e Planejamento. **Pesquisa Nacional de Demografia e Saúde da Criança e da Mulher – PNDS 2006**: dimensões do processo reprodutivo e da saúde da criança. Brasília; 2009. http://bvsmms.saude.gov.br/bvs/publicacoes/pnds_crianca_mulher.pdf. Accessed: 6 Mar. 2021.
23. UNFPA. World Population Dashboard. Brazil- Overview Family planning. **United Nations Population Fund**, 2020 Available at: <https://www.unfpa.org/data/world-population/BR>. Accessed: 6 Mar. 2021.
24. PRIETSCH, S. O. M. et al. Gravidez não planejada no extremo sul do Brasil: Prevalência e fatores associados. **Cadernos de Saude Publica**, v. 27, n. 10, p. 1906–1916, 2011.
25. GUTTMACHER INSTITUTE. **Adding it up. Investing in Sexual and Reproductive Health 2019**. p. 56, 2020. Available at: https://www.guttmacher.org/sites/default/files/report_pdf/adding-it-up-investing-in-sexual-reproductive-health-2019.pdf. Accessed: 6 Mar. 2021.
26. SINGH, Susheela et al. **Abortion worldwide 2017: uneven progress and unequal Access**. New York: Guttmacher Institute, 2017. Available at: https://www.guttmacher.org/sites/default/files/report_pdf/abortion-worldwide-2017.pdf. Accessed 28 Feb. 2021.
27. BRASIL. Decreto-lei n. 2.848, de 7 de dezembro de 1940. Código Penal. **Diário Oficial** [da União], Brasília, 31 dez. 1940. Available at: <https://www2.camara.leg.br/legin/fed/declei/1940-1949/decreto-lei-2848-7-dezembro-1940-412868-publicacaooriginal-1-pe.html>. Accessed: 25 feb. 2021
28. BRASIL. Supremo Tribunal Federal. Arguição de Descumprimento de Preceito Fundamental n. 54. Relator: Min. Marco Aurélio. Brasília, DF, 12 de abril de 2012. **Diário da Justiça Eletrônico**, Brasília, 30 abr. 2013. Available at: <http://stf.jus.br/portal/processo/verProcessoAndamento.asp?numero=54&classe=ADPF&codigoClasse=0&origem=JUR&recurso=0&tipoJulgamento=M>. Accessed: 25 Feb. 2021.
29. WORLD HEALTH ORGANIZATION. **Unsafe abortion: global and regional estimates of the incidence of unsafe abortion and associated mortality in 2008**. 6th edition. Geneva, Switzerland: World Health Organization, 2011. Available at: https://apps.who.int/iris/bitstream/handle/10665/44529/9789241501118_eng.pdf?sequence=1. Accessed: 6 Mar. 2021.
30. BRASIL. Ministério da Saúde. **Zika Vírus**. 24 nov 2020. Available at: <https://www.gov.br/saude/pt-br/assuntos/saude-de-a-a-z-1/z/zika-virus>. Accessed 6 Mar. 2020.

31. BORGES, A. L. V. et al. Women's reproductive health knowledge, attitudes and practices in relation to the Zika virus outbreak in northeast Brazil. **PLOS ONE**, v. 13, n. 1, p. e0190024, 3 Jan. 2018.
32. BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. **Boletim Epidemiológico** Monitoramento dos casos de arboviroses urbanas causados por vírus transmitidos por Aedes (dengue, chikungunya e zika), semanas epidemiológicas 1 a 53, 2020. N 03, Vol 52, Jan 2021. Available at: https://www.gov.br/saude/pt-br/media/pdf/2021/fevereiro/01/boletim_epidemiologico_svs_3.pdf. Accessed: 6 Mar. 2021.
33. BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. **Boletim Epidemiológico** Monitoramento dos casos de arboviroses urbanas transmitidas pelo Aedes (dengue, chikungunya e Zika), Semanas Epidemiológicas 01 a 52. N02, Vol 52, Jan 2020. Available at: <https://antigo.saude.gov.br/images/pdf/2020/janeiro/20/Boletim-epidemiologico-SVS-02-1-.pdf>.
34. BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. **Boletim Epidemiológico** . Monitoramento dos casos de dengue, febre de chikungunya e doença aguda pelo vírus Zika até a Semana Epidemiológica 52 de 2018. N 04, Vol 50, Jan 2019. Available at: <https://antigo.saude.gov.br/images/pdf/2019/janeiro/28/2019-002.pdf>. Accessed: 6 Mar. 2021.
35. DINIZ, D. **Zika in Brazil: women and children at the center of the epidemic**. Brasília: Letras Livres; 2017. Available at: https://anis.org.br/wp-content/uploads/2020/07/Zika-in-Brazil_Anis_2017-1.pdf. Accessed: 28 Feb 2021.
36. STRAUSS, Anselm; CORBIN, Juliet. **Pesquisa Qualitativa: técnicas e procedimentos para desenvolvimento de teoria fundamentada**. 2. ed. Porto Alegre: Artmed, 2008. 288 p. Tradução Luciane de Oliveira da Rocha.
37. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3:77-101.
38. HURST, D. J. Benefit Sharing in a Global Context: Working Towards Solutions for Implementation. **Developing World Bioethics**, v. 17, n. 2, p. 70–76, 2017.
39. ALVAREZ-CASTILLO, F.; FEINHOLZ, D. Women in developing countries and benefit sharing. **Developing World Bioethics**, v. 6, n. 3, p. 113–121, 21 Sep. 2006.
40. Brazil. IBGE. **Pesquisa nacional por amostra de domicílios : síntese de indicadores 2015**. Coordenação de Trabalho e Rendimento. 2016. Available at: <https://biblioteca.ibge.gov.br/visualizacao/livros/liv98887.pdf>. Accessed: 6 Mar. 2021.
41. MOURA, A. A.; MELLO, M. J. G. DE; CORREIA, J. B. Prevalence of syphilis, human immunodeficiency virus, hepatitis B virus, and human T-lymphotropic virus infections and coinfections during prenatal screening in an urban Northeastern Brazilian population. **International Journal of Infectious Diseases**, v. 39, p. 10–15, Oct. 2015.

42. LEAL, Maria do Carmo et al. **Trajetória do pré-natal ao pós-parto no SUS**. Rio de Janeiro: FIOCRUZ/ENSP, 2019. 1 p. Available at: https://www.arca.fiocruz.br/bitstream/icict/40649/2/Infografico_peregrinacao.pdf. Accessed: 6 Mar. 2021.
43. BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. **Boletim Epidemiológico**. Monitoramento integrado de alterações no crescimento e desenvolvimento relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas, até a Semana Epidemiológica 52 de 2018. N. 08. Vol 50; 2019. Available at: <http://portalarquivos2.saude.gov.br/images/pdf/2019/marco/22/2019-001.pdf>. Accessed 6 Mar. 2021.
44. FOSTER, A. M. et al. The 2018 Inter-agency field manual on reproductive health in humanitarian settings: revising the global standards. **Reproductive Health Matters**, v. 25, n. 51, p. 18–24, 2017.
45. WENHAM, C. et al. Women are most affected by pandemics — lessons from past outbreaks. **Nature**, v. 583, n. 7815, p. 194–198, 8 Jul. 2020.

2.3 Reflections on research ethics in a Public Health Emergency: Listening to Brazilian women affected by Zika

Ilana G. Ambrogi^{1 2}

Luciana Brito²

Sergio Rego³

¹ Programa de Pós-graduação em Bioética Ética Aplicada e Saúde Coletiva, Fundação Oswaldo Cruz, Rio de Janeiro, RJ.

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

³ Fundação Oswaldo Cruz (Fiocruz), Rio de Janeiro, RJ.

At the time this dissertation was finalized, this article is in process for submission.

Abstract:

In Brazil, the epicenter of the Zika crisis disproportionately affected Afro Brazilian and poor women living in backlands or in municipalities with scarce welfare resources. The gendered consequences of the epidemic have been explicit from the start, exposing how intersectional lenses are central to better understand the impact of public health emergencies in the lives of women and girls. During the outbreak, there was an intense demand for Zika-affected children as well as women as caregivers to be research participants. To learn from their experiences would be an important step towards improving ethical procedures for protecting participants in vulnerable situations during a public health emergency. With that objective, we investigated how women experienced their participation in biomedical research by analyzing their narratives. A two-year long longitudinal qualitative study in five Brazilian sites located in the epicenter of the Zika epidemic was performed using mixed methods: ethnography with women from two distinct Brazilian states and individual semi-structured interviews with five women who are community leaders in five different states. All women in the study were mothers or grandmothers of Zika-affected children. Thematic analysis was used for the evaluation of the data. We found that women were excluded from any sort of benefit subsequent to the research they participated in. Structural power dynamics influenced how they experienced research participation aggravating vulnerabilities. Bureaucratic procedures, such as the approval of research protocols by local IRB (Institutional Review Board), were insufficient in protecting participants because these instruments were unable to recognize the power structures that render women vulnerable, such as significant lack of healthcare access, ability to read, and medical paternalism. Communitarian mobilization, through WhatsApp groups, was found to be an important mechanism to challenge oppressive structures and initiate change. Public health emergencies should include community-based participatory strategies in order to transform unequal structures of power and effectively promote participant protection.

Keywords: Research ethics, Zika, vulnerability, public health emergency responses, community engagement.

Introduction:

The outbreak of microcephaly cases in Brazil initially detected in 2015 and later linked to the Zika virus brought global scientific interest to the most affected areas.¹ The scientific race to investigate the bodies of the women and children affected was intensified in February 2016 with the declaration of Public Health Emergency of International Concern (PHEIC) by the World Health Organization (WHO).² Although the Zika virus had been known to science since the 1950s, prior to the Zika epidemic in Brazil, nothing was known about Zika virus effects on women, pregnancy, embryo, fetus, or child development, and what later became known as congenital Zika syndrome (CZS).^{3,4,5,6} The sexual and reproductive effects of Zika was an unexpected novelty to scientists and clinicians all over the world.⁷

According to the last cumulative data published by the WHO, Brazil has the highest number of CZS cases and Zika infection in the world⁸. After four years of the epidemic, Brazil continues to be the epicenter of CZS and Zika infections. Zika virus and its mosquito vector circulates in Brazil to this day, and new cases of CZS are diagnosed every year.⁹ There is a positive correlation among Zika, poverty, CZS cases, poor infrastructure, and lack of basic sanitation.¹⁰ It should come with no surprise that the majority of CZS cases are concentrated in the Brazilian Northeast, one of the regions with the lowest HDI (Human Development Index) and highest rates of adolescent pregnancies in the country.^{11,12} There are also other important factors that contribute to this picture, such as gender inequality, as well as lack of access to sexual and reproductive health, safe abortions, and information.^{7,10,13}

The most affected are young, poor, Afro Brazilian, indigenous women with little formal education living in poor areas of the country.^{9,10,14} The majority of them depend on the public health system (Sistema Único de Saúde - SUS) for care, and caregivers of affected children are mostly women.^{14,15} Together with their children, women live taxing days filled with itineraries of care and many unknowns.^{15,16,17} Yet, all that is known about this novel global phenomenon of a mosquito borne disease found to have significant sexual and reproductive consequences come from the participation of women and children for the advancement of science.¹⁷ The hope in science as a way to find answers, along with feelings of altruism, was an important mechanism for many women when making a decision to collaborate with researchers, allowing for invasive procedures on themselves and their children.^{16,17} From the biomolecular mechanism of the virus to the social impacts of the epidemic, multinational, multidisciplinary

global research consortiums were avidly seeking for participants.^{18,19,20} The Zika epidemic and its consequences are a gendered issue.^{7,10,21} Research involving those most affected by Zika are in the context of the intersectionality of poverty, unmet health and socio-economic needs, racial and gender disparities, and low levels of formal education.¹⁰

Our historical past as a colony and the persistence of coloniality²² with the maintenance of subservient relation to the world's economical leaderships has long enabled paternalistic, racist, and misogynistic values to shape our relations. History has shown that science and healthcare practice are not immune to this.^{23,24,25} How investigational practices impact the women and children affected by Zika becomes then an important question. Although the international interest in Zika has decreased significantly, the women and families affected continue to have unanswered questions, many unmet needs and rights violated. What is the impact when a research team goes to a region with significant needs and inequalities during a public health emergency and takes information, time, and samples for the sake of science never to return? With an intersectional feminist approach,^{10,26,27} this study investigated how Zika-affected women experienced research, paying particular attention to research participant protection processes such as informed consent and benefit sharing, and what impact it had on their lives.

Methodology and Materials:

This is a mixed methods longitudinal qualitative study performed during 2017-2019 with Brazilian women affected by Zika. In order to examine how participation or invitation to participate in research affected the women, two methods were utilized: ethnography with women from two Brazilian states (Rio de Janeiro and Alagoas) and individual semi-structured interviews with five women who are community leaders in five different Brazilian states, four of which are located in the Northeast region and one in the Southeast. The focus was on their experiences when they participated or were invited to participate in research regarding Zika, CZS, themselves, and/or their affected children. One or more members of the research team followed women during their daily routines intermittently throughout these years, be it at home or at the community associations of mothers and caregivers of children affected by Zika. Observations also involved the digital space of groups in WhatsApp, a popular messaging phone application in Brazil, where many mothers and caregivers share their experiences, questions, and advice amongst themselves. WhatsApp groups administrators, who are mothers,

grandmothers, or caregivers of Zika-affected children met during the field work and invited some of the research team members to participate in the online application. The observations on WhatsApp focused on topics regarding research participation, what was said regarding being approached to participate in research, return of exam results done during research participation, as well as any return of information acquired through research, such as benefit sharing. This acquaintanceship with their experiences since the Zika virus entered their lives during this part of the study was fundamental in order to develop the semi-structured guide for the interview performed with five of the women.

For all interactions, the reason for the presence of a research member was explained and permission was granted for the qualitative study of their experiences. Many interactions happened in community settings such as associations, rehabilitation centers, and/or other events. The research team also used these moments to explore the women's perceptions regarding research, and more specifically investigate their experiences and the significance of the informed consent form in their lives. At times, we asked permission to gather a group of women for narrative-oriented conversations on this topic or to individually listen to them.

Semi-structured interviews were conducted with five women, mothers, or grandmothers of a child affected by the Zika virus. They lived in different states; each of these locations was majorly affected by the Zika epidemic and have women's associations centered around children affected by Zika.²⁸ Four of the women interviewed were leaders of these associations and were considered community leaders by their peers. The interviews were 30-60 minutes long and took place in a location of the women's choosing. Some were at the women's homes, some at the community association centers. Although they were semi structured and topic guided, the rapport established during previous interactions with the women allowed for the interviews to take place as conversations. The interview instrument was elaborated to explore women's perceptions and understandings when participating or when asked to participate in research regarding Zika on them or their children. Questions regarding their emotions, reactions, and implications in relation to the informed consent form were investigated. From there, topics that emerged related to their situation of being part of a scientific investigation were further explored.

All interviews were recorded and transcribed for later analysis. Measures to maintain the confidentiality of the identity of the women participants were taken by codifying the interviews

and transcriptions with numbers and by not utilizing any identifying information in the description of the data. For the field work with ethnography-based narrative-oriented conversations, filed notes taken by the researchers were shared via password protected files and did not contain any identifying information; dates and the state where the interaction happened were the only localizing information. Thematic analysis was used when evaluating the data.²⁹ Two researchers coded the interviews and concepts were grouped to form themes. This allowed for a conceptual understanding of the themes that emerged from the data, without being previously formulated by the researcher.³⁰ With this method, a reflective interpretation of the concepts found in the data was possible. Data from both methodological approaches were analyzed together and are presented here as one construct for understanding the event being studied.

Whenever possible and appropriate, researchers engaged in benefit sharing practices, providing information regarding social benefits available to the women or orienting them to resources where they could find a requested support, like pro-bono lawyers or medical orientation. Plans to return research findings were discussed with the interviewed women. A digital copy of the final product in accessible language as well as individual conversations via WhatsApp were agreed as possible means for reporting the research findings.³¹ The research protocol was reviewed and approved by the Escola Nacional de Saúde Pública Sergio Arouca -ENSP/Fiocruz Research Ethics committee– CAAE: 73740017.0.0000.5240. This study complied with the International Ethical Guidelines for Health-related Research Involving Humans. Both written and oral informed consent were used as a continued process, according to the level of literacy of the participants and given the low risk level of this type of qualitative research interaction that mostly happened in community settings. And it was very similar to the interactions that normally happened in their gatherings and with people in their community.

Results & Discussion:

Although an important characteristic of this research is its longitudinal aspect, most of the women's narratives were related to experiences lived during the peak of the epidemic and the correlated scientific rush for answers. Some of the women's perspectives regarding their and their children's participation in research changed as a result of their interaction with researchers and the study procedures they experienced along the years. Initially, closer to the first outbreak, science was an important source of hope and there was great attention paid to the scientific

authorities. Although the hope in science persisted, questions regarding research's potential to positively impact their lives started to arise and the ideas surrounding the investigational process started to change. By sharing discontent with the conduct of researchers, there was the realization of a collective experience that was unique to them – being affected by the Zika epidemic in Brazil. With a voice that was no longer sole, they started to challenge the ways procedures were being carried out.

Lack of recognition of the women's efforts and benefits in research

Science provided many answers that helped these women understand what had happened to them, their pregnancies, and their children. They appreciated when the scientific way of inquiry and investigations provided information that made sense in helping explain how the mosquito-borne infection changed their lives. They also knew and understood that science was pervasively present in their routines. Among the multiple medications, medical procedures, signs and symptoms the child presented, women knew the importance of observation and the study of events that posed questions to which answers were needed.^{16,17} Research participation, however, needed to be applicable in their lives; the meaning of science was derived from the potential and/or perceived benefits it would bring to their children. As one woman explained: *“Research can help our children a lot, they can bring a lot of benefits, right?!”*

As it has been described, benefit from participating in research can be interpreted in a variety of ways: from a rational decision as a way to access better care when living in low resource settings,³² to positive feelings of altruism, to even a possible ‘inclusion benefit’,^{33,34} that is, having a better outcome due to the fact of being part of a study. An important challenge during public health emergencies due to novel disease processes such as CZS and recently during the COVID-19 pandemic, is that there is no known, evidence-based treatment for the new condition. Consequently, the potential risks and benefits of medical treatment can start to very closely resemble those of research interventions. Seen as fundamental and boosted by the mainstream media exposure during the initial phases of the outbreak, research and scientists were welcomed and sought after as a means to collaborate and get the answers needed. Interestingly, throughout the multitude of encounters with national and international research teams, this perception started to suffer modifications due to two main reasons: an overwhelming excess of research propositions and/or participation and a lasting void of any return of findings or benefits.

As mentioned, the declaration of the public health emergency of international concern due to the consequences of Zika-related infections drew global attention and brought research efforts to Brazil. Cases were concentrated in low resource regions, and affected women were referred to university hospitals or research institutions. These places became the reference centers for the care of women and children affected by Zika. Pediatric and other specialists would be available only a few days of the week or month and all those in need of a visit would be scheduled on those days. Many women and children live far away from the reference centers and depend on state or municipal chartered transportation.¹⁴ Coordination of care occurred so all of the Zika-affected cases would be seen on the same day. With this, there was also a concentration of Zika researchers seeking for participants. After participating in dozens of studies, women started feeling harassed by the researchers waiting in the halls of the hospital. One of the women interviewed described her experience, which she noted other women shared, as an “*excess of exposure*” to research solicitations and participations. Going for a medical appointment and being approached by several different research teams asking for names and personal information was experienced as “*a mafia of research*”. She further explained the experience as “*everyone is traumatized*”.

Coupled with feeling overwhelmed with so many research participations, several women said that these studies had “*no meaning*” to them. When asked why, the answer was related to the lack of “*benefit*”. At first sight, one could think this is an issue of “*therapeutic misconception*,” where research participants fail to recognize the difference between research and treatment by understanding that the purpose of the study is to only benefit those enrolled.³⁵ However, women thought of research benefits not as a direct or immediate benefit, but as something well-founded scientifically and that would provide improvements in the future, that would come to be. In addition, the lack of benefit was always related to the absence of result dissemination, benefit sharing, or follow-up from the researchers. As another woman explained, “*This research was not important to me at all. I would like to be informed of what happened, but for me, it was not worth it*”. Women’s experience with research was profoundly marked by the absence of findings dissemination and also a lack of benefit sharing. A prominent and recurring complaint in the interviews was that the results from all the exams, imaging, and testing done on their bodies or biological samples collected from them and their children were never returned to them. They also expressed sadness and indignation that outcomes of the investigations were never shared.

This must be understood in the context of these women's lives. They are the primary caregivers of children with significant specialized needs and with many pathologies that are mostly unknown, even to the medical experts. They know the value of science, and they participated in the studies with the hope they would bring benefits. Benefit sharing has been described as "the sharing of whatever accrues from the utilization of biological resources, community knowledge, technologies, innovations or practices".³⁶ Benefit, in benefit sharing, is defined as anything that "contributes to the well-being of an individual and/or a given community (e.g. by region, tribe, disease-group, etc.)".³⁷ One participant explained it well: "*many researchers had some benefit. I am not saying financially, but they had some benefit in evaluating our children, and we didn't have any benefit*". Sharing of findings is an ethical imperative³¹ already announced in the Declaration of Helsinki,³⁸ but it is also to be understood as one of the possible ways to share benefits. Even if it is a null finding, participants should be informed and thanked.^{37,39} When studies are carried out without any recognition of the women's efforts and benefits never reach them, research becomes, in fact, meaningless.

The excessive and concerted research solicitations and participation coupled with the lack of benefit sharing were some of the reasons many women attributed to declining participating in studies. These aspects of how research was experienced by the women led to changes in how women perceived and engaged with research. This is an important finding to be appreciated as it can lead to loss of a community's value regarding science as a mechanism to find reliable answers to problems in society, opening precedent for other types of, perhaps less predictable, explanations to take on this role.¹⁶ More importantly, it demonstrates how women themselves value their participation in the research and understand that they were alienated from obtaining any return for their efforts. Women, particularly poor women in developing countries, are excluded from benefit sharing and their needs are neglected.⁴⁰ It also draws attention to the ill effects of uncoordinated and unchecked scientific races in public health emergency settings and the importance of community participation in all phases of study design and implementation.^{41,42,43}

Structural power dynamics in research aggravate gendered vulnerabilities

The Belmont Report, a global reference for basic ethics and guidelines for research with humans, states clear boundaries for medical care and research. Although it acknowledges that

they can happen at the same time, the distinction between an investigational procedure guided by a hypothesis and standard practice with a known expectation of benefit is sharply made.⁴⁴ Yet, there are challenges establishing and recognizing these boundaries in several circumstances.^{35,45} Emerging diseases in emergency situations in which resources are scarce and people are living with many unmet needs can shift perspectives and dispute these boundaries.^{43,45} Thus, an intersectional and comprehensive approach is important to better understand how health emergencies implicate in this issue.

There were several factors that made the distinction between research and care difficult for women in this study. One woman told us: *“It is all mixed together. You don’t know the difference because you are in a doctor’s appointment and at the same time there are tons of questions. At the same time, there are people filling out questionnaires with you, and in the same room your son is being seen [by a health provider]. So, you can’t separate what day is research and what day is regular medical treatment”*. Here, as the Belmont report predicted as a possibility, is a situation where care and research are happening concurrently. Lack of adequate communication and time for decision have all been characterized as important issues to attend to when doing research with humans in order to allow for adequate informed consent, particularly in situations of public health emergencies.^{41,43,46} But what makes the distinction difficult goes beyond just the participant-researcher dyad; it has to do with the broader contexts and power structures.

Women reported that the quality of care in the same hospital where they have been taking their children from the beginning of the epidemic has decreased significantly with the passing of the years. When studies were abundant, children would be evaluated *“right away”* and the *“mother”* would leave the hospital after a visit with *“something”*, such as an evaluation result or further testing. This type of attention has *“stopped”* completely; imaging evaluations that would be performed expediently currently *“take 5 months”* according to women. They related that this change is due to lack of financial resources from the international organizations, *“American and British”*, that are no longer doing research in the centers. Confusion between care and research experienced by the women is not a straightforward case of ‘therapeutic misconception’ but informed by many structural factors that can involve a strategic choice for better care and some evaluation of risk and benefits that goes beyond the clinical assessment.^{32,47} Especially considering that CZS is a novel condition, and the majority of

affected women are poor with difficult access to health care, the alternative to research might be an “empty choice”.⁴⁸

Women in this study described multiple times how the informed consent form did not carry any other meaning to them, other than being a procedure they needed to do. As a woman told us, *“You go for an appointment, and even before the visit starts, there are five or six different types of researchers asking you questions. One study is for this, another is for that. A ton of forms that you have to sign right away. No one explained what it was regarding, and I would just start signing.”* When asked about the informed consent papers, many of women did not have the forms; a few reporting losing them or throwing them away; some said they were never given a copy. Others signed the form but did not know how to read what was stated in there. This demonstrates severe inadequacies in the process of consenting. At a minimum, three aspects should be fulfilled in the process of discussing informed consent – information, comprehension, and voluntariness,⁴⁴ none of which seem to have been satisfied. Informed consent is a mechanism intended to guarantee the opportunity to choose to participate or not in a study.⁴⁴ The idea of choice can be problematic because it would also require an analysis of individual freedom and structural power dynamics.⁴⁸ Choice cannot be assessed just from within the researcher-participant relationship.

The Declaration of Helsinki⁴ brings attention to the fact that “Some research populations are vulnerable”, but it fails to further qualify these vulnerabilities.³⁸ It has been argued that poverty and social exclusion defined as relational and fluid processes “driven by unequal power relationships interacting across an economic, political, social and cultural dimension and operating at different levels, including individual, household, group, community, country and global levels”⁴⁹ characterize as vulnerabilities in medical research because it leads to health inequalities and diminished autonomy.⁵⁰ The experience of a woman in search of care for her child exemplifies this: *“When my son was hospitalized for treatment, the doctor gave me a lot*

⁴ The Declaration of Helsinki established in 1964 is used here as an important historical mark for research ethics. However, in the past couple of decades this declaration has suffered significant modifications, leading Brazil to no longer be a signatory, particularly due to changes that unfairly affects the most vulnerable populations. Conselho Nacional de Saúde. Comissão Nacional de Ética em Pesquisa. Análise técnica da Comissão Nacional de Ética em Pesquisa sobre o Projeto de Lei nº 200/2015. Available at: https://conselho.saude.gov.br/Web_comissoes/conep/aquivos/Analise-tecnica-Lei200-2015.pdf. Accessed: 15 Apr 2021. DINIZ, D; GUILHEM, D. Declaração de Helsinki: uma história de dignidade. Centro Feminista de Estudos e Assessoria – CFEMEA, 08 Mar 2000. Available at: <https://www.cfemea.org.br/index.php/colecao-femea/68-numero-086-marco-de-2000/214-declaracao-de-helsinki-uma-historia-de-dignidade>. Accessed: 15 abr 2021.

of forms for us to sign right away, on the first encounter. That had never happened to me before. It was a lot a paper! Since I really wanted to get care there because it was a reference hospital [for specialty care]. I signed everything. But I did not understand right away what it meant”.

Inequality and powerlessness⁵⁰ lived by the women due to a patriarchal, racist, classist political, social, and economic structures add important layers of vulnerabilities to their lives. In this scenario, even more conservative definitions of ‘coercion’ and ‘undue influence’ can happen almost seamlessly. According to the Belmont Report, ‘coercion’ and ‘undue influence’ would only happen when participant’s voluntariness is affected by an “overt threat of harm” or “excessive, unwarranted, inappropriate or improper reward or other overture in order to obtain compliance”.⁴⁴ Although they also recognize that there are situations where these issues can be presented in a subtle manner, there is no greater analysis of the effects on people in vulnerable or crisis situations. The declaration of Helsinki also alerts to these issues and brings attention to situations where potential study participants are “in a dependent relationship with the physician”.³⁸ The recommendation in these cases is that consent should then be sought by an independent party.

Even within these narrow definitions, women described situations that would fit these constraints, as when they were told by the principal investigator of research, who is also their personal clinician, that they should not participate in other studies. Or when a health provider from the public service announced on the WhatsApp groups about task force days for examination and stated: “*You have to participate in these tests*” without saying that they were part of a study. Here, “undue influence” is particularly concerning for at least three important reasons. 1- In most cases, Zika-affected children and women receive care on task force days of examinations, given the scarcity of resources and their remote locations.¹⁶ They are used to these announcements about the days they will have care, so distinguishing care from research before they make plans to go is essential. 2- Answers regarding whether or not this was part of research were not given publicly in the group, only individually to those women who asked privately. 3- Most of the affected women and children are dependent on the public health system to keep immunization report cards and other public health records. These are usually required in order for them to receive certain public social benefits and enroll in school.⁵¹

To more adequately evaluate the structural character of the power dynamics, in place when studies are conducted primarily with women and children living a public health crisis due to a

novel disease, we need to depart from narrowly focusing on the participant-researcher dyad.⁵² Particularly in situations as those encountered in this study, where there are market inequalities, the concept of ‘structural coercion’ is important to understand the experiences lived by the women and children. Structural coercion shifts the focus from the individual and accounts to structural – social, economic, political, and cultural – contexts that take part in a person’s decision to enroll in a study.⁵² This concept is based on the understandings of ‘structural violence’ as harmful social arrangements that “are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people”.⁵³ The justification mentioned above by one of the women interviewed of not having another option to obtain specialty care other than by signing the research papers shows how ‘structural coercion’ works on vulnerabilities. ‘Structural coercion’ can be identified when a woman related that she would not question the physician because he/she would not allow for that kind of intimacy, so she explained that she didn’t find it was really necessary to ask. The coercive forces are not rooted solely in the participant-researcher relationship but have been established by gendered social and economic power dynamics outside the dyad. More importantly, the intervention to transform this also lies outside of the participant-researcher relationship.⁵²

A fundamental factor to diminish ‘structural violence’ as already reflected by Paul Farmer is the guarantee of rights.⁵³ The provision of health via the Sistema Unico de Saúde (SUS), the Brazilian public health care system, allows women to decline research. As exemplified when a mother told us that after feeling unrecognized and disrespected by researchers and given that care tied with research had worsened, she stopped taking her child to the research hospital, and would instead go to another public hospital to obtain care. If free accessible public health were not an option, it is likely that her decision would be a different one. In fact, that has been observed in the cases when specific interventions are not available in the public system, but attainable via study enrolment.^{48,52} This adds evidence to the fundamental role of SUS along with other social and economic protections in the prevention of ‘structural violence’, ‘structural coercion’, and social exclusion, also guaranteeing rights and improving research.^{50,53}

When thinking of ‘structural violence’ and patriarchal structures present in our society, it is difficult not to feel pain when a mother told us: “*Nowadays, there are physicians that don’t even look at my child. They don’t find it as important because the [research] boom stopped*”. Many women reported feeling “*used*” and that their children are not “*guinea pigs*”¹⁶. One

woman said: “*During research you feel like an object, right? Because, you know, they poke the children a lot*”. At the same time that this points to a lack of recognition, it also claims it.¹³ Objects are not human, and don’t make decisions.⁵⁴ It did not take long for women to organize a WhatsApp group, one the main ways of communication, to talk about their feelings regarding the investigational work performed on their children’s bodies as well as their own. Women felt the importance of recognition for their identity and autonomy.⁵⁵ These feelings of disrespect, collectively shared, as they reflected on their experiences in groups, was a motivational basis for collective action.⁵⁵ One of the women explained: “*I think today they [the researchers] are more careful, several mothers got together in [WhatsApp] groups to complain*”. Others said they stopped participating in research all together. These attitudes can be interpreted as a “collective fight for recognition”.⁵⁵

Final Considerations:

The ethical protection of research participants goes beyond typical bureaucratic procedures, such as the approval of research protocols by a local IRB (Institutional Review Board). Our findings support what has already been described as a significant limitation of consent; by itself it is insufficient for ensuring ethical research practices.⁴³ Although our study is limited by its purposive sampling, we focused on the longitudinal experiences of women with leadership roles in the community. Women were excluded from all sorts of research-related benefit, highlighting the importance of benefit sharing. We were able to identify that there are structural issues that affect research participant protection. Consequently, interventions should address the broader context of inequalities and injustices. Particularly, in public health emergency settings, in which situations of vulnerability are aggravated, attention should be paid to the participants and their communities in evaluating the structural power dynamics that affect research participation. In the context of poverty, social exclusion and many unmet needs, even community engagement can be insufficient in preventing vulnerabilities from exploitation and structural coercion.⁵⁶ Yet, our findings point to the importance of having research protocols that are community-based designed, involving grassroots movements.^{43,57,58} The building of a collective voice was a significant mechanism to challenge oppressive structures and initiate change. Community-based participatory strategies should be founded on feminist values, promoting shifts in power and transforming oppressive structures.^{10, 27,57}

Now, women living the Zika legacy of caring for their families and having their sexual and reproductive livelihood under threat are experiencing yet another unprecedented public health emergency due to the SARS-CoV-2 virus. The COVID-19 pandemic has further disproportionately impacted women and girls, deepening vulnerabilities and worsening inequalities.⁵⁹ Our findings add evidence to the importance of having a gender-transformative approach, placing women and girls at the center of public health emergency responses, not only to improve research participant protection but also to advance gender equality and prevent vulnerabilities and exploitation. In places with marked inequalities such as Brazil in the Global South, a feminist approach is fundamental to appreciate the intersecting oppressions that disproportionately affect women and girls. This lens should be used in all phases of public health emergency preparedness and response. Research should be developed and performed in ways that are centered on women and girls, safeguarding their rights.

Acknowledgments

We acknowledge all research participants for their time. We also would like to express our gratitude to the European Union's Horizon 2020 Research and Innovation Programme under ZIKAlliance Grant Agreement no. 734548 for supporting this study. The funders of this study had no participation in study design, data collection or analysis, data interpretation, writing or editing of this report.

Contributors

We declare no conflicts of interest. All authors contributed equally to this manuscript. I. G. Ambrogi, L. Brito, and S. Rego participated in all phases of the study, interpreted the data, critically revised the manuscript, approved the final version, and agreed to be accountable for all aspects of the work.

References

1. OLIVEIRA, J. F. DE et al. The global scientific research response to the public health emergency of Zika virus infection. **PLOS ONE**, v. 15, n. 3, p. e0229790, 12 Mar. 2020.
2. WORLD HEALTH ORGANIZATION. **WHO statement on the first meeting of the International Health Regulations (2005) (IHR 2005) Emergency Committee on Zika virus and observed increase in neurological disorders and neonatal malformations**. 1 Feb 2016a. Available at <https://www.who.int/news-room/detail/01-02-2016-who-statement-on-the-first-meeting-of-the-international-health-regulations->

- (2005)-(ihr-2005)-emergency-committee-on-zika-virus-and-observed-increase-in-neurological-disorders-and-neonatal-malformations. Accessed: 24 Feb. 2021.
3. DICK, G. W.; KITCHEN, S.; HADDOW, A. Zika Virus (I). Isolations and serological specificity. **Transactions of the Royal Society of Tropical Medicine and Hygiene**, v. 46, n. 5, p. 509–520, Sep. 1952.
 4. BAUD, D. et al. An update on Zika virus infection. **The Lancet**, v. 390, p. 2099–2109, 2017.
 5. DE OLIVEIRA, W. K. et al. Infection-related microcephaly after the 2015 and 2016 Zika virus outbreaks in Brazil: a surveillance-based analysis. **The Lancet**, v. 390, n. 10097, p. 861–870, 2017.
 6. MARTINES, R. B. et al. Pathology of congenital Zika syndrome in Brazil: a case series. **The Lancet**, v. 388, n. 10047, p. 898–904, 2016.
 7. VÉLEZ, A. C. G.; DINIZ, S. G. Inequality, Zika epidemics, and the lack of reproductive rights in Latin America. **Reproductive Health Matters**, v. 24, n. 48, p. 57–61, 2016.
 8. WORLD HEALTH ORGANIZATION/PAHO. **Zika cases and congenital syndrome associated with Zika virus reported by countries and territories in the Americas, 2015 - 2018. Cumulative cases.** 04 January 2018. Available at: https://www.paho.org/hq/index.php?option=com_docman&view=download&category_slug=cumulative-cases-pdf-8865&alias=43296-zika-cumulative-cases-4-january-2018-296&Itemid=270&lang=en. Accessed: 5 Mar. 2021.
 9. BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. **Boletim Epidemiológico: Situação epidemiológica da síndrome congênita associada à infecção pelo vírus Zika, 2015 a 2020.** N 04. Vol 52; 2021a. Available at: https://www.gov.br/saude/pt-br/media/pdf/2021/fevereiro/11/boletim_epidemiologico_svs_4.pdf. Accessed: 25 Feb. 2021.
 10. WENHAM, C. et al. Gender mainstreaming as a pathway for sustainable arbovirus control in latin America. **PLoS Neglected Tropical Diseases**, v. 14, n. 2, p. 1–7, 2020.
 11. BRASIL. IPEA. Desenvolvimento Humano Nas Macrorregiões Brasileiras. 2016b. Available at: http://www.ipea.gov.br/portal/images/stories/PDFs/livros/livros/20160331_livro-idhm.pdf. Accessed: 25 Feb. 2021.
 12. BRASILb. Ministério da Saúde. Secretaria de Vigilância em Saúde. **Sistema de Informações sobre Nascidos Vivos – SINASC.** Available at: <http://tabnet.datasus.gov.br/cgi/defthtm.exe?sinasc/cnv/nvuf.def>. Accessed: 25 Feb. 2021.

13. DINIZ, D.; BRITO, L. Epidemia provocada pelo vírus Zika: informação e conhecimento. **Revista Eletrônica de Comunicação, Informação e Inovação em Saúde**, v. 10, n. 2, p. 1–5, 2016.
14. AMBROGI, I. G.; BRITO, L.; DINIZ, D. The vulnerabilities of lives: Zika, women and children in Alagoas State, Brazil. **Cadernos de saúde pública**, v. 36, n. 12, p. e00032020, 2021.
15. FREITAS, P. S. S. et al. How do mothers feel? Life with children with congenital Zika syndrome. **International Journal of Gynecology and Obstetrics**, v. 148, n. S2, p. 20–28, 2020.
16. DINIZ, Debora; BRITO, Luciana. Uma epidemia sem fim: zika e mulheres. In: RIFIOTIS, Theophilos; SEGATA, Jean (org.). **Políticas etnográficas no campo da moral**. Porto Alegre: UFRGS, 2019. p. 169-181. Available at: http://www.aba.abant.org.br/administrator/product/files/129_00135322.pdf. Accessed: 5 Mar. 2021.
17. DINIZ, D. **Zika: Do Sertão nordestino à ameaça global**. Rio de Janeiro: Civilização Brasileira. 2016.
18. ZIKALLIANCE (org.). **ZIKAlliance: A Global Alliance for Zika Virus Control and Protection**. Available at: <https://zikalliance.tghn.org/>. Accessed: 5 mar. 2021.
19. ZIKAPLAN (org.). **ZikaPLAN: Preparedness Latin American Network**. Available at: <https://zikaplan.tghn.org/>. Accessed: 5 Mar. 2021.
20. ZIKACTION (org.). **International ZIKAction Consortium**. Available at: <https://zikaction.org/>. Accessed: 5 Mar. 2021.
21. DAVIES, S. E.; BENNETT, B. A gendered human rights analysis of Ebola and Zika: Locating gender in global health emergencies. **International Affairs**, v. 92, n. 5, p. 1041–1060, 2016.
22. REGO, S.; PALÁCIOS, M. Ethics, global health and Zika virus infection: a view from Brazil. **Revista Bioética**, v. 24, n. 3, p. 430–434, 2016.
23. REGO, S. **A formação ética dos médicos: saindo da adolescência com a vida (dos outros) nas mãos** [online]. Rio de Janeiro: Editora FIOCRUZ, 2003, 183 p. ISBN 978-85-7541-324-1. <https://doi.org/10.7476/978857541324>
24. BRANDT, A. M. Racism and Research: The Case of the Tuskegee Syphilis Study. **The Hastings Center Report**, v. 8, n. 6, p. 21, 1978.
25. RODRIGUEZ, M. A.; GARCÍA, R. First, do no harm: The US sexually transmitted disease experiments in Guatemala. **American Journal of Public Health**, v. 103, n. 12, p. 2122–2126, 2013.

26. LARSON, E. et al. 10 Best resources on... intersectionality with an emphasis on low- and middle-income countries. **Health Policy and Planning**, v. 31, n. 8, p. 964–969, 1 Oct. 2016.
27. DINIZ, D. Perspectivas e articulações de uma pesquisa feminista. In: STEVENS, Cristina; OLIVEIRA, Susane Rodrigues de; ZANELLO, Valeska. **Estudos feministas e de gênero: articulações e perspectivas**, Ilha de Santa Catarina: Mulheres, 2014. p. 11-21. Available at: http://repositorio.unb.br/bitstream/10482/16349/1/LIVRO_EstudosFeministasedeGeneroArticula%C3%A7%C3%B5es.pdf. Accessed: 25 Feb. 2021.
28. MATOS, S. S.; SILVA, A. C. R. DA. “Nada sobre nós sem nós”: associativismo, deficiência e pesquisa científica na Síndrome Congênita do Zika vírus. **Ilha Revista de Antropologia**, v. 22, n. 2, p. 132–168, 23 Nov. 2020.
29. BRAUN, V.; CLARKE, V. Using thematic analysis in psychology. **Qualitative Research in Psychology**, v. 3, n. 2, p. 77–101, Jan. 2006.
30. STRAUSS, Anselm; CORBIN, Juliet. **Pesquisa Qualitativa: técnicas e procedimentos para desenvolvimento de teoria fundamentada**. 2. ed. Porto Alegre: Artmed, 2008. 288 p. Tradução Luciane de Oliveira da Rocha.
31. TAYLOR, J. Reporting research findings to participants is an ethical imperative. **BMJ**, v. 367, n. November, p. 16324, 4 Nov. 2019.
32. MFUTSO-BENGO, J. et al. Why do individuals agree to enrol in clinical trials? A qualitative study of health research participation in Blantyre, Malawi. **Malawi Medical Journal**, v. 20, n. 2, p. 37–41, 19 Aug. 2008.
33. SCHMIDT, B. et al. Do sick newborn infants benefit from participation in a randomized clinical trial? **Journal of Pediatrics**, v. 134, n. 2, p. 151–155, 1999.
34. LANTOS, J. D. The “inclusion benefit” in clinical trials. **The Journal of Pediatrics**, v. 134, n. 2, p. 130–131, Feb. 1999.
35. HENDERSON, G. E. et al. Clinical Trials and Medical Care: Defining the Therapeutic Misconception. **PLoS Medicine**, v. 4, n. 11, p. e324, 27 Nov. 2007.
36. ORGANIZATION OF AFRICAN UNITY (OAU). African model legislation for the protection of the rights of local communities, farmers, and breeders, and to the regulation of access to biological resources. **OAU Model Law**, v. 8, 2000. Available at: <https://www.wipo.int/edocs/lexdocs/laws/en/oau/oau001en.pdf>. Accessed: 5 Mar. 2021.
37. HUGO ETHICS COMMITTEE. Hugo Ethics Committee statement on benefit sharing April 9, 2000. **Clinical Genetics**, v. 58, n. 5, p. 364–366, 2000.
38. WORLD MEDICAL ASSOCIATION. **Declaration of Helsinki: ethical principles for medical research involving human subjects**. 9 July 2018. Available at:

- <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>. Accessed: 5 Mar. 2021.
39. EDITORIAL. How a simple ‘thank you’ could improve clinical trials. **Nature**, v. 563, n. 7731, p. 293–294, 13 nov. 2018. Available at: <https://www.nature.com/articles/d41586-018-07410-0>. Accessed: 5 Mar. 2021.
 40. ALVAREZ-CASTILLO, F.; FEINHOLZ, D. Women in developing countries and benefit sharing. **Developing World Bioethics**, v. 6, n. 3, p. 113–121, 21 Sep. 2006.
 41. SULLIVAN, M. et al. Researcher and Researched-Community Perspectives: Toward Bridging the Gap. **Health Education & Behavior**, v. 28, n. 2, p. 130–149, 30 Apr. 2001.
 42. MARTINEZ, L. S. et al. Clinical and Translational Research and Community Engagement: Implications for Researcher Capacity Building. **Clinical and Translational Science**, v. 5, n. 4, p. 329–332, Aug. 2012.
 43. NUFFIELD COUNCIL ON BIOETHICS. Research in global health emergencies: ethical issues. **Nuffield Council on Bioethics**, n. January, p. 276, 2020. Available form: <https://www.nuffieldbioethics.org/publications/research-in-global-health-emergencies/>. Accessed: 5 Mar. 2021.
 44. UNITED STATES. Department of Health, Education, And Welfare. The National Commission for The Protection of Human Subjects of Biomedical And Behavioral Research. Office of The Secretary. **THE BELMONT REPORT: Ethical principles and guidelines for the protection of human subjects of research**. Washington: 1979. Available at: https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf. Accessed: 5 Mar. 2021.
 45. HELGESSON, G. Can and should the research–therapy distinction be maintained? Reflections in the light of innovative last-resort treatment. **Research Ethics**, v. 15, n. 2, p. 1–14, 18 Apr. 2019.
 46. FALB, K. et al. The ethical contours of research in crisis settings: five practical considerations for academic institutional review boards and researchers. **Disasters**, v. 43, n. 4, p. 711–726, 2019.
 47. RAVINETTO, R. M. et al. Participation in medical research as a resource-seeking strategy in socio-economically vulnerable communities: Call for research and action. **Tropical Medicine and International Health**, v. 20, n. 1, p. 63–66, 2015.
 48. KINGORI, P. The ‘empty choice’: A sociological examination of choosing medical research participation in resource-limited Sub-Saharan Africa. **Current Sociology**, v. 63, n. 5, p. 763–778, 13 Sep. 2015.
 49. RAVINETTO, R. M. et al. Rapid Response to Revising the Declaration of Helsinki. Medical research in socio-economically disadvantaged communities: a delicate balance.

- BMJ**, 17 June 2013. Available from: <https://www.bmj.com/content/346/bmj.f2837/rr/650200>. Accessed on 5 Mar. 2021.
50. POPAY, J. Understanding and tackling social exclusion. **Journal of Research in Nursing**, v. 15, n. 4, p. 295–297, 5 Jul. 2010.
51. BRASIL. Casa civil. **Portaria nº 5.209, de 17 de setembro de 2004**. Regulamenta a Lei nº 10.836, de 9 de janeiro de 2004, que cria o Programa Bolsa Família, e dá outras providências. Brasília, 2004. Available from: http://www.planalto.gov.br/ccivil_03/_ato2004-2006/2004/decreto/d5209.htm#:~:text=Regulamenta%20a%20Lei%20no,que%20lhe%20confere%20o%20art. Accessed: 5 Mar. 2021.
52. FISHER, J. A. Expanding the Frame of “Voluntariness” in Informed Consent: Structural Coercion and the Power of Social and Economic Context. **Kennedy Institute of Ethics Journal**, v. 23, n. 4, p. 355–379, 2013.
53. FARMER, P. E. et al. Structural violence and clinical medicine. **PLoS Medicine**, v. 3, n. 10, p. 1686–1691, 2006.
54. FREIRE, Paulo. **Education for critical consciousness**. London: Continuum, 2005. First published 1974.
55. HONNETH, Axel. **Luta por reconhecimento: a gramática moral dos conflitos sociais**. São Paulo: Editora 34, 2009. 296 p. Tradução de Luiz Repa.
56. NYIRENDA, D. et al. Structural coercion in the context of community engagement in global health research conducted in a low resource setting in Africa. **BMC Medical Ethics**, v. 21, n. 1, p. 90, 21 Dec. 2020.
57. ANOKO, J. N. et al. Community engagement for successful COVID-19 pandemic response: 10 lessons from Ebola outbreak responses in Africa. **BMJ Global Health**, v. 4, p. 1–4, 2020.
58. SHAH, S. K.; MILLER, F.; FERNANDEZ LYNCH, H. The role of community engagement in addressing bystander risks in research: The case of a Zika virus controlled human infection study. **Bioethics**, p. bioe.12806, Nov. 2020.
59. WENHAM, C.; SMITH, J.; MORGAN, R. COVID-19: the gendered impacts of the outbreak. **The Lancet**, v. 395, n. 10227, p. 846–848, 2020.

3 EDITORIAL

3.1 Research ethics and the Zika legacy in Brazil

Debora Diniz, PhD, is an anthropologist by training and professor at the Law Faculty,
University of Brasilia, Brazil.

Ilana Ambrogi, MD, is physician by training, a PhD candidate at Oswaldo Cruz Foundation
and a researcher at Anis -Institute of Bioethics in Brasilia, Brazil.

*This editorial was published on *Developing World Bioethics*
v. 17, n. 3, p. 142–143, December 2017. DOI: 10.1111/dewb.1217536 n°.12*

It is presented here as it was published by the journal.

Research ethics and the Zika legacy in Brazil

The Zika virus has not left Brazil. While Brazil declared the end to the emergency situation for the epidemic in May 2017,¹ the mosquitoes continue to be abundant and the effects of sexual transmission are still poorly understood.² On 21 August 2017, a child with Zika congenital syndrome was born in Santana do Ipanema, a rural city of Alagoas, the state with the lowest Human Development Index (HDI) and the highest rate of teenage pregnancy in the country.³ She was the fifth child born to a poor family that survives on a governmental cash benefit program. The mother had Zika's symptoms during the pregnancy and did not use repellent. She is the typical woman affected by Zika in Brazil.

Zika is a tropical disease characterized by mild symptoms and the main vector is the *Aedes aegypti* mosquito. Until the Brazilian outbreak, the risk of vertical transmission of the virus, that is, from the pregnant woman to the fetus, was not yet known. There are already more than 14,000 children reported as suspected cases of congenital Zika syndrome and almost 3,000 with the diagnosis confirmed.⁴ There are children from the first wave of the outbreak, from 2015, who are still waiting for a diagnosis. They were reported as suspected cases in the delivery room, but the investigation has not yet yielded a diagnosis. One of the reasons for the delay is that the families of these children live far away from the health centers with the technical conditions to perform exams required by the national health policy for diagnosis.⁵

Congenital Zika virus syndrome is a spectrum of signs and symptoms, with microcephaly being the most common sign. The first suspicion of a new disease circulating in Brazil came with the increased numbers of children born with reduced head circumference - in

October of 2015, there was talk of an epidemic of microcephaly.⁶ Almost two years after the first reports, medical research has advanced and it is now known that there are children affected by Zika virus that did not present with microcephaly at birth.⁷

In an epidemic of new disease, doctors assume the scientific spirit of inquiry. The diagnoses are tentative and the prognoses almost non-existent. The uncertainty of science is a sign of prudent waiting for new knowledge, but it paints a bleak picture for the families affected. The Zika epidemic mirrors Brazilian inequality: at the epicenter are rural cities, black and poor women; in Rio de Janeiro, one of the most affected states outside the Northeast, are women with a similar profile living in the slums or "favelas".

Zika in Brazil wasn't only an epidemic, it was the emergence of a new way of getting sick. These two phenomena gave rise to two health practices: assistance and research. On the one hand, children need early stimulation, daily medications, dietary supplements or medical technologies. On the other hand, science needs the solidarity of women so that research is completed on them and their children. The result is an intense demand from women as caregivers and research subjects. They are known as the "mothers of Zika" or "mothers of angels". As it has been observed in other epidemics the public health issues to prevent the proliferation of the mosquitoes, Zika infections or unplanned pregnancies were taken out of focus and a transient interventionist approach took center stage.⁸

In the remote areas of Brazil, the doctors who provide medical care became the researchers.⁹ The country's major research institutes are in the center-south regions, far from the everyday life of the families affected by Zika. Research teams were formed with national and international networks: the collection of samples are done at the bedside and further analysis at far away institutions. If, on the one hand, this is a promising meeting for the development and decentralization of medical research in the country, on the other hand, new ethical issues emerge. Two of these ethical issues deserve special mention because, when combined, they increase the vulnerability of the women enrolled in research: specifically medical paternalism and the overlap between care and research.

¹The health minister made the announcement in May 2017, however the official ordinance was only published in July. PORTARIA N° 1.682, DE 30 DE JULHO DE 2017: Declara o encerramento da Emergência em Saúde Pública de importância Nacional (ESPIN) por alteração do padrão de ocorrência de microcefalias no Brasil e desativa o Centro de Operações de Emergências em Saúde Pública (COES). http://www.poderesau.de.com.br/novosite/imagens/06.07.2017_1.pdf

²Clinical Guidance for Healthcare Providers for Prevention of Sexual Transmission of Zika Virus | Zika Virus | CDC (no date). Available at: <https://www.cdc.gov/zika/hc-providers/clinical-guidance/sexualtransmission.html> [Accessed 22 August 2017].

³For an analysis of the situation of women and children affected by the Zika epidemic in Alagoas, see: Diniz, Debora. *Zika in Brazil: women and children at the center of the epidemic*. Brasília. LetrasLivres. 88pp <http://anis.org.br/wp-content/uploads/2017/06/Zika-in-Brazil_Anis_2017.pdf>

⁴BRASIL. Secretaria de Vigilância em Saúde - Ministério da Saúde. Monitoramento integrado de alterações no crescimento e desenvolvimento relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas. Boletim Epidemiológico n. 24, Semana Epidemiológica 28/2017. Disponível em: http://portal.arquivos.saude.gov.br/imagens/pdf/2017/agosto/16/BE-2017_024-Monitoramento-integrado-de-alteracoes-no-crescimento-e-desenvolvimento-relacionadas-a-infeccao-pelo-virus-Zika.pdf. [Acesso em 22 ago. 2017].

⁵An imaging study is mandatory. Some states, such as Alagoas, require it to be a CT scan. The state only has two CT scanners.

⁶On the history of the arrival of the Zika virus in Brazil and the first discoveries, refer to: Diniz D. *Zika: from Brazilian backlands to a global threat*. London. Zed Books. 2017.

⁷Ventura CV et al. (2016) 'Zika: neurological and ocular findings in infant without microcephaly', *The Lancet*. Elsevier, 387(10037), p. 2502. [https://doi.org/10.1016/s0140-6736\(16\)30776-0](https://doi.org/10.1016/s0140-6736(16)30776-0).

⁸Schuklenk U. (2014) 'Bioethics and the Ebola Outbreak in West Africa', *Developing World Bioethics*. Wiley Online Library, 14(3), pp. ii-iii. <https://doi.org/10.1111/dewb.12073>.

⁹The first identification of the Zika virus in the amniotic fluid was done by a doctor from a remote region of Paraíba.

Brazil is a country where social inequality seeps through access to health services. The health system is mixed (private and public), but children with Zika congenital syndrome are in their vast majority cared for in the public health system. This means that they are totally dependent on the state for medical care. In rural and remote cities, the doctor is a figure of economic and social status. The ethical principle of autonomy is rarely discussed among doctors and almost unknown as a right of patients.

With the superimposition of the physician who provides care with the researching physician, paternalism slips from medical practice to research. There are two consequences dealing with the *paternalistic medical researcher*: first, the intimidation for women to refuse participation in research protocols, as they fear the loss of care; and second, the anguish over the uncertainty of the children's prognosis is replaced by the hope of scientific advancement. It is the same figure in a white coat who offers care and hope.

Compliance with the ethical standards for reviewing research protocols is not enough to deal with the doctor-researcher's paternalistic morality. Since the beginning of the epidemic, Brazil's national ethical review system, known as CEP-CONEP, has made an effort to act at the time of the health emergency. Almost every woman we talked to had copies of informed consent, even though not all of them understood what they had signed. We would venture to say that the ethical review rite is being fulfilled, especially because the research groups involved are from reference health centers in the country and internationally, with personnel already trained for the ethical formalities of the research protocols.

The challenge, however, is a new one. Families have already understood that there is an urgency for knowledge, whether by the solidarity with science or scientific competition. The main fear is that they will be forgotten when Zika is no longer on the research agenda. They do not want to be just research subjects, but families looking for health care. They want to be cared for and not just investigated by science. If women do not directly confront the researching physician, be it through subservience or sagacity in daily survival, they have organized virtually as a group.

We participate in almost a dozen virtual chat groups of mothers.¹⁰ The groups are not homogeneous, some are local, while others are national. The participation of physicians in some of the groups alters the spontaneous dynamics among women, replicating the question-and-answer practices of the physician-patient hierarchy. The groups led by physicians bring benefits to the families - in particular, it improves access to health care in remote areas. On the other hand, they are like closed communities controlled by the local physician researcher: there are recommendations for families to not participate in research of competing groups or to not share tests results with other researchers.

One of the groups composed only by mothers is called "My son is not a guinea pig."¹¹ In the group, women share terms of informed consent, discuss new opportunities of participation in scientific research, or the biomedical vocabulary used to describe their children. They

question the medical diagnoses, and they record the children in crisis in order to discuss among themselves forms of care. Slowly, they come to fuel the idea of an association for the struggle for rights. They begin to build a collective voice to face the authority of the doctor-researcher. There is, however, a risk in this political movement for some women from remote cities who are integrally dependent on the local physician, the same one collecting data for research institutes: confrontation with medical power can mean the child's helplessness in assistance.

The reality that we describe in Brazil might not be different from other Latin American countries affected by Zika. Paternalism is common in the relationship between doctors and vulnerable patients, and more specifically black, rural, poor women patients. In order for women and children to not be threatened by lack of health care, research ethics has to be a priority in countries where medical paternalism is the moral of care.

Children continue to be born affected by Zika, and thousands more are under the gaze of the doctor-researcher. Women have already embraced the urgency of research ethics to guarantee the rights of their children. It is time for the doctor-researcher to return to the books and learn the basics of bioethics. One of the basics is that medical paternalism does not go with patient's autonomy.

Debora Diniz
Ilana Ambrogi

DEBORA DINIZ, PhD, is an anthropologist by training and professor at the Law Faculty, University of Brasilia, Brazil.

ILANA AMBROGI, MD, is physician by training, a PhD candidate at Oswaldo Cruz Foundation and a researcher at Anis - Institute of Bioethics in Brasilia, Brazil.

¹⁰WhatsApp is a very popular mobile phone application, a widely used method of text messaging among mothers. There are hundreds of messages every day.

¹¹Debora Diniz was invited to be in a chat group composed by mothers as an observer.

4 FINAL CONSIDERATIONS

A public health crisis reveals inequalities; it worsens them, but it does not *a priori* create them (FARMER, 2005; RICHARDSON, 2020). As this dissertation was being finalized, the COVID-19 pandemic considerably accentuated the crisis in Brazil. Many women remain unable to access sexual and reproductive services to meet their contraceptive needs or to obtain prenatal care (ROSAS; PARO, 2021; UNITED NATIONS POPULATION FUND; 2020; DE SOUZA SANTOS et al., 2020). Again, they are being placed in unconscionable risk and emerging data have started to show some of the devastating consequences. Brazil leads the international charts on maternal deaths due to COVID-19 (NAKAMURA-PEREIRA et al., 2020). Many died without getting to the ICU or having a chance to obtain respiratory support (TAKEMOTO et al., 2020). Since the official announcement of the COVID-19 pandemic, it has been established that pregnant women should be considered a risk group for worse outcomes of SARS-CoV-2 infection (BRASIL, 2020b). Yet, no priority for vaccinations and services have been implemented (BRASIL, 2021b). Several ordinances by the ministry of health put in place during the pandemic effectively limit access to SRH and legal abortion services (BRASIL, 2020c; BRASIL, 2020d; RONDON, 2020). The Brazilian government revoked an official report that emphasized the essentiality of SHR services during the pandemic (CANCIAN; CARVALHO, 2020). Four days after it was first published, two out of the three governmental public health officials that signed the report were fired (JORNAL NACIONAL, 2020).

Women are the most affected in health emergencies (WENHAM et al., 2020). The increase in violence against women, decrease in sexual and reproductive health services and declining economical livelihood of women during COVID-19 sadly proves that we have not implemented the necessary changes to prevent and correct these effects (WHENHAM et al., 2020; ANIS – INSTITUTO DE BIOÉTICA, 2020). It would be fair to wonder why “lessons” from past outbreaks were not learned. A decentralized and broad approach is necessary for adequate analysis of the gender inequality created by a racist colonial capitalist patriarchal system of power. Without structural system transformations, lessons will never be fully learned and adequate change is unlikely to be achieved (GONZALEZ, 2020). An anti-racist anti-imperialist anti-capitalist eco-socialist feminism provides paths to challenge the reproduction of systemic intersectional oppressions and inequalities that prevent public health preparedness to effectively protect the most vulnerable women and girls (ARRUZZA; BHATTACHARYAI; FRASER, 2019).

The Zika outbreak in Brazil revealed how the legacy of this epidemic transcends the virus and the biological aspects of the infection. Brazilian women and girls living in the

Northeast of Brazil were already at the greatest risk, even prior to the virus' arrival in the national territory. And the aftermath of Zika infection did not end when the epidemiological curves no longer indicated numerical reasons for alarm: it has persisted until the present and perpetuates into the future of women and girls. It persists as cascades of vulnerabilities (LUNA, 2019) as well as widened social and economic inequalities based on assumptions of gender. Our findings indicate that reproductive rights, including the right to abortion, are central and urgent issues during emergency health crises and that responses must include the protection and actualization of these rights. It also shows the intersectionality of gender, socioeconomic status, class, racial identity, geography, and educational level as important factors that can compound vulnerabilities. More importantly, it revealed some of the mechanisms of how these intersections work to hamper sexual and reproductive health and rights of women and girls affected by Zika.

We demonstrated here how economic and social inequalities marked by the assumptions of gender hierarchy made women and girls vulnerable to the effects of the epidemic. These effects, in turn, triggered a cascade of vulnerabilities (LUNA, 2019), further consolidating inequalities. Past and current public health emergencies have already shown that this cycle will repeat again (HAWKES; BUSE, 2013; SMTH, 2019). The COVID-19 pandemic's effects on women and girls also exposes how those in most vulnerable situations are disproportionately affected (WENHAM; SMITH; MORGAN, 2020). With public health emergencies becoming more frequent, there is urgency to reframe how we approach the ethical issues that these crises raise and create responses that will effectively guarantee women's and girls' rights, gender equality and reproductive justice. The work presented here serves to expose some of the historical and political structures that maintain gender inequality by challenging the assumptions of gender hierarchy and placing women and girls in the center of the discussion.

Altogether, a bioethical analysis of the findings of this feminist research indicates that the exclusion of the sexual and reproductive health and rights discussion from public discourse and political agendas rendered women and girls even more vulnerable to the impacts of the epidemic. The effects of this omission became unequivocal given the unexpected sexual and reproductive consequences of this particular public health emergency (DINIZ et al., 2020). Without contraception access, SRH information, and the right to an abortion, women and girls were left unprotected and their destinies start to seem as if they were immutable (RICHARDSON, 2020). This is not unique to Zika; sexual and reproductive health and rights have been overlooked and dismissed in several other public health emergencies (HARMAN, 2016; SMITH, 2019; RILEY et al., 2020). The uniqueness of Zika is that this epidemic was

only a PHEIC because of the reproductive consequences given the possibility of vertical transmission of the virus, from the pregnant women to the fetus, leading to CZS. Thus, it would not be a leap to conclude that the response to deal with Zika would have to necessarily involve a discussion about reproductive rights. How can we explain the silence regarding sexual and reproductive health and rights?

Patriarchal structures impose gender hierarchy by controlling sexual and reproductive health and rights discourse (HEISE et al, 2019; HOOKS, 2015). In turn, the praxis and even the theory of reproductive health and rights is regulated within the constraints of patriarchy – the technology of the political regimen of gender (DINIZ, 2014). Analyzing Zika through a feminist bioethics perspective revealed some of the inner workings of this apparatus and its effects on reproductive rights and women's lives. It demonstrated how the absence of reproductive rights, including the right to abortion, places women and girls in vulnerable situations. It showed how significant omission of sexual and reproductive health and rights and marked social inequalities compound vulnerabilities and help to erase the epidemic and its effects. This dissertation demonstrated that women were soon forgotten, marginalized, their issues not part of the public agenda. Researchers and the resources they had once brought returned to the Global North as quickly as they had first arrived. As such, the Zika epidemic in Brazil allows for a singular analysis of the effects of gender inequality during a public health emergency. It reifies the essentiality of reproductive health and rights and the need for it to be a central aspect of any emergency response.

When abortion is distorted to not be understood as an integral part of sexual and reproductive health, the ensuing effect is the suppression of all discussions regarding sexual and reproductive issues with the direct impact on women's and girls' health and lives, as this research demonstrated. To talk about Zika necessarily means to talk about sexual and reproductive rights, particularly the right to abortion. With these topics being impeded by historical patriarchal structures of power, Zika would soon disappear from the discourse, and so it did. And together with Zika, women and girls disproportionately affected by the virus remained out of the focus of public policy responses (HARMAN, 2016). The evidence gathered in this dissertation confirms and supports that a public health response to Zika needs to contain the right to abortion, access to sexual and reproductive health, the right to raise a child with CZS with dignity, access to treatments, the right to information, the right to benefit sharing from research, the right to participate in every aspect of research development, and the right to social protection policies, such as cash transfer programs (DINIZ, 2017). These findings add

evidence to the importance of the reproductive justice framework when dealing with public health emergencies.

The analysis of the Zika epidemic through a feminist lens revealed how patriarchal structures impose its epistemology regarding public health emergencies, consequently shifting the focus away from those most affected – women and girls of reproductive age. If public health emergency responses were centered on women and girls, Zika would not have had such devastating consequences. This holds true in any public health emergency; Zika just made it undeniable (DEBRUIN; LIASCHENKO; MARSHALL, 2012; HARRIS; SILVERMAN; MARSHALL, 2016; DAVIES; BENNETT, 2016). As such, it is an ethical imperative to resist and transform the structures that allow women and girls to be omitted from the responses in crisis situations. The ethical issues raised by this research regarding reproductive rights and public health emergencies are three pronged. It brings evidence to: 1- the need for a feminist approach, based on a reproductive justice lens, in order to reframe the questions, unmask inequalities, and create new paths to preparedness; 2- Abortion as essential health need in any public health emergency response, as it is in everyday life; 3-the lasting negative effects on the lives of women and girls when they are not at the center of emergency responses.

For a response to a public health emergency to be ethical, it must utilize a reproductive justice framework with the comprehension of reproductive rights, reproductive health, and social justice as crucial components of public health. In this sense, solutions must be centered in women, girls and their communities in the development of all aspects of prevention, preparedness, mitigation, response and recovery efforts from research to public policies proposals and implementation. The Zika epidemic, as an important case study for public health emergencies, reifies that sexual and reproductive rights, including the right to abortion, must be a central issue in any emergency responses. It is urgent that public health emergency responses stop perpetuating reproductive injustices and gender inequalities.

REFERENCES

AGÊNCIA FIOCRUZ DE NOTÍCIA. **Dengue**. 4 Jul 2013. Available at: <https://agencia.fiocruz.br/dengue-0>. Accessed: 25 feb. 2021.

ANIS – INSTITUTO DE BIOÉTICA. (Brasil) (org.). **Protegendo o futuro pós pandemia: recomendações para o aperfeiçoamento da renda básica emergencial para mulheres**. Brasília, Agosto, 2020. Available at: <https://anis.org.br/wp-content/uploads/2020/09/ANIS--RENDIA-EMERGENCIAL-.pdf>. Accessed: 5 Mar. 2021.

ANKER, M. Addressing sex and gender in epidemic-prone infectious diseases. **World Health Organisation (WHO)**, p. 1–46, 2007.

ARGENTINA. Constituição (2020). Ley nº 27610, de 30 de dezembro de 2020. **Acceso A La Interrupcion Voluntaria del Embarazo**. Available at: <http://servicios.infoleg.gob.ar/infolegInternet/verNorma.do?id=346231>. Accessed: 4 Mar. 2021.

ARRUZZA, Cinzia; BHATTACHARYA, Tithi; FRASER, Nancy. **Feminism for the 99%: a manifesto**. London: Verso, 2019. Kindle Edition.

ASSIS, W. F. T. Do colonialismo à colonialidade: expropriação territorial na periferia do capitalismo. **Caderno CRH**, v. 27, n. 72, p. 613–627, 2014.

BAUD, D. et al. An update on Zika virus infection. **The Lancet**, v. 390, p. 2099–2109, 2017.

BEARAK, J. et al. Unintended pregnancy and abortion by income, region, and the legal status of abortion: estimates from a comprehensive model for 1990–2019. **The Lancet Global Health**, v. 8, n. 9, 2020.

BIETSCH, K.; WILLIAMSON, J.; REEVES, M. Family Planning During and After the West African Ebola Crisis. **Studies in Family Planning**, v. 51, n. 1, p. 71–86, 2020.

BRADY, O. J. et al. The association between Zika virus infection and microcephaly in Brazil 2015-2017: An observational analysis of over 4 million births. **PLoS medicine**, v. 16, n. 3, p. e1002755, 2019.

BRASILa. Ministério da Saúde (MS). **Indicadores de mortalidade: Taxa de mortalidade infantil, 2000-2011**. Available at: <http://tabnet.datasus.gov.br/cgi/idb2012/c01b.htm>. Accessed: 25 Feb. 2021.

BRASILb. Ministério da Saúde. Secretaria de Vigilância em Saúde. Sistema de Informações sobre Nascidos Vivos – SINASC. Available at: <http://tabnet.datasus.gov.br/cgi/deftohtm.exe?sinasc/cnv/nvuf.def>. Accessed: 25 Feb. 2021.

BRASIL. Decreto-lei n. 2.848, de 7 de dezembro de 1940. Código Penal. **Diário Oficial** [da União], Brasília, 31 dez. 1940. Available at: <https://www2.camara.leg.br/legin/fed/declei/1940-1949/decreto-lei-2848-7-dezembro-1940-412868-publicacaooriginal-1-pe.html>. Accessed: 25 Feb. 2021.

BRASIL. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. **Manual dos comitês de mortalidade materna**. – 3. ed. – Brasília : Editora do Ministério da Saúde, 2009a. 104. Available at: http://bvsmms.saude.gov.br/bvs/publicacoes/manual_comites_mortalidade_materna.pdf. Accessed: 25 Feb. 2021.

BRASIL. **Lei nº 12.015, de 7 de agosto de 2009**. Altera o Título VI da Parte Especial do Decreto-Lei nº 2.848, de 7 de dezembro de 1940 - Código Penal, e o art. 1º da Lei nº 8.072, de 25 de julho de 1990, que dispõe sobre os crimes hediondos, nos termos do inciso XLIII do art. 5º da Constituição Federal e revoga a Lei nº 2.252, de 1º de julho de 1954, que trata de corrupção de menores. 2009b. Available at: http://www.planalto.gov.br/ccivil_03/_ato2007-2010/2009/lei/112015.htm#:~:text=L12015&text=LEI%20N%C2%BA%2012.015%2C%20DE%207%20DE%20AGOSTO%20DE%202009.&text=Alterar%20o%20T%C3%ADulo%20VI%20da,C%C3%B3digo%20Penal%2C%20e%20o%20art.&text=5o%20da%20Constitui%C3%A7%C3%A3o%20Federal,trata%20de%20corrup%C3%A7%C3%A3o%20de%20menores. Accessed: 28 Feb 2021.

BRASIL. Supremo Tribunal Federal. Arguição de Descumprimento de Preceito Fundamental n. 54. Relator: Min. Marco Aurélio. Brasília, DF, 12 de abril de 2012. **Diário da Justiça Eletrônico**, Brasília, 30 abr. 2013. Available at: <http://stf.jus.br/portal/processo/verProcessoAndamento.asp?numero=54&classe=ADPF&codigoClasse=0&origem=JUR&recurso=0&tipoJulgamento=M>. Accessed: 25 Feb. 2021.

BRASIL. Supremo Tribunal Federal. **Ação Direta De Inconstitucionalidade (ADI) 5581**. 24 Aug. 2016a. Available at: <http://portal.stf.jus.br/processos/detalhe.asp?incidente=5037704>. Accessed: 27 Feb. 2021.

BRASIL. IPEA. Desenvolvimento Humano Nas Macrorregiões Brasileiras. 2016b. Available at: http://www.ipea.gov.br/portal/images/stories/PDFs/livros/livros/20160331_livro-idhm.pdf. Accessed: 25 Feb. 2021.

BRASIL. Ministry of Health. **LIRAA aponta 357 municípios em situação de Risco para dengue, zika e chikungunya**. 28 Nov 2017a. Available at: <https://portalarquivos2.saude.gov.br/images/pdf/2017/novembro/28/LIRAA-e-nova-campanha.pdf>. Accessed: 25 Feb. 2021.

BRASIL. Ministério da Saúde . Secretaria de Vigilância em Saúde. **Boletim Epidemiológico: Monitoramento dos casos de dengue, febre de chikungunya e febre pelo vírus zika até a semana epidemiológica 52, 2016. N 03. Vol 48; 2017b**. Available at: <https://antigo.saude.gov.br/images/pdf/2017/abril/06/2017-002-Monitoramento-dos-casos-de-dengue--febre-de-chikungunya-e-febre-pelo-v--rus-Zika-ate-a-Semana-Epidemiologica-52--2016.pdf>. Accessed: 25 Feb. 2021.

BRASIL. Ministério do Desenvolvimento Regional. **Um mosquito não é mais forte que um País inteiro**. 18 Jan 2017c. Available at: <https://www.gov.br/dnocs/pt-br/assuntos/noticias/um-mosquito-nao-e-mais-forte-que-um-pais-inteiro>. Accessed: 28 Feb. 2021.

BRASIL. Supremo Tribunal Federal. **Arguição de Descumprimento de Preceito Fundamental (ADPF) 442**. 08 March 2017d. Available at: <http://portal.stf.jus.br/processos/detalhe.asp?incidente=5144865>. Accessed: 27 Feb. 2021.

BRASIL. Supremo Tribunal Federal. Audiência Pública. **Interrupção Voluntária da Gravidez - ADPF 442**. Relatora: Ministra Rosa Weber. 2018. Available at: <http://www.stf.jus.br/arquivo/cms/audienciasPublicas/anexo/TranscrioInterrupovoluntriadagravidez.pdf>. Accessed: 27 Feb. 2021.

BRASIL. Ministério da Saúde. **Departamento de Informática do SUS (DATASUS)**. Óbitos maternos por ano do óbito segundo região: período: 1996-2019. 2019a. Available at: <http://tabnet.datasus.gov.br/cgi/tabcgi.exe?sim/cnv/mat10uf.def>. Accessed: 25 Feb. 2021.

BRASIL. Ministério da Economia. Instituto de Pesquisa Econômica Aplicada (Ipea). **Cadernos Ods - Ods 3**. 2019b. Available at: https://www.ipea.gov.br/portal/images/stories/PDFs/livros/livros/190829_cadernos_ODS_objetivo_3.pdf. Accessed: 4 Mar. 2021.

BRASIL. Ministério da Saúde . Secretaria de Vigilância em Saúde. **Boletim Epidemiológico: Centro de Operações de Emergências em Saúde Pública: COVID 19**. 06; 2020a. Available at: <https://portalarquivos.saude.gov.br/images/pdf/2020/April/03/BE6-Boletim-Especial-do-COE.pdf>. Accessed: 25 Feb. 2021.

BRASIL. Ministério da Saúde. Secretaria de Atenção Especializada à Saúde. Departamento de Atenção Hospitalar, Domiciliar e de Urgência. **Protocolo de manejo clínico da Covid-19 na Atenção Especializada**. 1. ed. rev. Brasília-DF. 2020b. Available at: https://bvsmms.saude.gov.br/bvs/publicacoes/manejo_clinico_covid-19_atencao_especializada.pdf. Accessed: 4 Mar. 2021.

BRASIL. Ministério da Saúde. **Portaria nº 2.282, de 27 de agosto de 2020**. Dispõe sobre o Procedimento de Justificação e Autorização da Interrupção da Gravidez nos casos previstos em lei, no âmbito do Sistema Único de Saúde-SUS. Diário Oficial da União. Brasília, 2020c. Available at: <https://www.in.gov.br/en/web/dou/-/portaria-n-2.282-de-27-de-agosto-de-2020-274644814>. Accessed: 5 Mar. 2021.

BRASIL. Ministério da Saúde. **Portaria nº 2.561, de 23 de setembro de 2020**. Dispõe sobre o Procedimento de Justificação e Autorização da Interrupção da Gravidez nos casos previstos em lei, no âmbito do Sistema Único de Saúde-SUS. Diário Oficial da União. Brasília, 2020d. Available at: <https://www.in.gov.br/en/web/dou/-/portaria-n-2.561-de-23-de-setembro-de-2020-279185796#:~:text=em%20lei%2C%20resolve%3A-,%20Art.,garantida%20a%20confidencialidade%20desses%20termos>. Accessed: 5 Mar. 2021.

BRASIL. Ministério da Saúde . Secretaria de Vigilância em Saúde. **Boletim Epidemiológico: Situação epidemiológica da síndrome congênita associada à infecção pelo vírus Zika**, 2015 a 2020. N 04. Vol 52; 2021a. Available at: https://www.gov.br/saude/pt-br/media/pdf/2021/fevereiro/11/boletim_epidemiologico_svs_4.pdf. Accessed: 25 Feb. 2021.

BRASIL. Núcleo Especializado de Promoção e Defesa dos Direitos das Mulheres (Nudem). Plano Nacional de Operacionalização da Vacinação Contra A Covid-19. Ofício Conjunto NUDEMs nº 001/2021. Relator: Ministro da Saúde, Sr. Eduardo Pazuello. **Defensoria Pública**.

15 fev. 2021b. Available at: <https://assets-institucional-ippg.sfo2.cdn.digitaloceanspaces.com/2021/02/Oficio-NUDEMs-01.2021-vers%C3%A3o-15.02-vacina-MS.pdf>. Accessed: 5 Mar. 2021.

BRIOZZO, L. et al. Overall and abortion-related maternal mortality rates in Uruguay over the past 25 years and their association with policies and actions aimed at protecting women's rights. **International Journal of Gynecology and Obstetrics**, v. 134, p. S20–S23, 2016.

CAMARA, B. S. et al. Effect of the 2014/2015 Ebola outbreak on reproductive health services in a rural district of Guinea: An ecological study. **Transactions of the Royal Society of Tropical Medicine and Hygiene**, v. 111, n. 1, p. 22–29, 2017.

CANCIAN, N; CARVALHO, D. Após pressão de Bolsonaro, Ministério da Saúde retira do ar nota técnica que cita acesso a aborto legal. **Folha de São Paulo**. São Paulo, 4 jun. 2020. Disponível em: <https://www1.folha.uol.com.br/equilibrioesaude/2020/06/apos-pressao-de-bolsonaro-ministerio-da-saude-retira-do-ar-nota-tecnica-que-cita-acesso-a-aborto-legal.shtml>. Accessed: 5 Mar. 2021.

CARDOSO, B. B.; VIEIRA, F. M. DOS S. B.; SARACENI, V. Aborto no Brasil: o que dizem os dados oficiais? **Cadernos de Saúde Pública**, v. 36, n. suppl 1, p. 1–13, 2020.

CARNEIRO Sueli. Mulheres em movimento. **revista Estudos Avançados**, v. 17, n. 49, p. 117–32, 2003.

CARNEIRO, Sueli. **Enegrecer o feminismo: a situação da mulher negra na América Latina a partir de uma perspectiva de gênero**. 06 March 2011a. Availbale at: <https://www.geledes.org.br/enegrecer-o-feminismo-situacao-da-mulher-negra-na-america-latina-partir-de-uma-perspectiva-de-genero>. Accessed: 4 Mar. 2021.

CARNEIRO, Sueli. **Racismo, Sexismo e Desigualdade no Brasil** (Consciência em Debate). Selo Negro Edições. 2011b. Kindle Edition. ISBN 978-85-87478-74-0

CONDE-AGUDELO, A.; BELIZÁN, J. M.; LAMMERS, C. Maternal-perinatal morbidity and mortality associated with adolescent pregnancy in Latin America: Cross-sectional study. **American Journal of Obstetrics and Gynecology**, v. 192, n. 2, p. 342–349, 2005.

DADOS, N.; CONNELL, R. The Global South. **Contexts**, v. 11, n. 1, p. 12–13, 14 Feb. 2012.

DAVIES, S. E.; BENNETT, B. A gendered human rights analysis of Ebola and Zika: Locating gender in global health emergencies. **International Affairs**, v. 92, n. 5, p. 1041–1060, 2016.

DE OLIVEIRA, W. K. et al. Infection-related microcephaly after the 2015 and 2016 Zika virus outbreaks in Brazil: a surveillance-based analysis. **The Lancet**, v. 390, n. 10097, p. 861–870, 2017.

DE SOUZA SANTOS, D. et al. Disproportionate Impact of Coronavirus Disease 2019 (COVID-19) Among Pregnant and Postpartum Black Women in Brazil Through Structural Racism Lens. **Clinical Infectious Diseases**, n. Correspondence, p. 1–2, 28 Jul. 2020.

DEBRUIN, D.; LIASCHENKO, J.; MARSHALL, M. F. Social justice in pandemic preparedness. **American Journal of Public Health**, v. 102, n. 4, p. 586–591, 2012.

DICK, G. W.; KITCHEN, S.; HADDOW, A. Zika Virus (I). Isolations and serological specificity. **Transactions of the Royal Society of Tropical Medicine and Hygiene**, v. 46, n. 5, p. 509–520, Sep. 1952.

DINIZ, D. Perspectivas e articulações de uma pesquisa feminista. In: STEVENS, Cristina; OLIVEIRA, Susane Rodrigues de; ZANELLO, Valeska. **Estudos feministas e de gênero: articula..es e perspectivas**, Ilha de Santa Catarina: Mulheres, 2014. p. 11-21. Available at: http://repositorio.unb.br/bitstream/10482/16349/1/LIVRO_EstudosFeministasedeG eneroArticula%C3%A7%C3%B5es.pdf. Accessed: 25 Feb. 2021.

DINIZ, D. **Zika: Do Sertão nordestino à ameaça global**. Rio de Janeiro: Civilização Brasileira. 2016.

DINIZ, D. **Zika in Brazil: women and children at the center of the epidemic**. Brasília: Letras Livres; 2017. Available at: https://anis.org.br/wp-content/uploads/2020/07/Zika-in-Brazil_Anis_2017-1.pdf. Accessed: 28 Feb 2021.

DINIZ, D.; BRITO, L. Epidemia provocada pelo vírus Zika: informação e conhecimento. **Revista Eletrônica de Comunicação, Informação e Inovação em Saúde**, v. 10, n. 2, p. 1–5, 2016.

DINIZ, D.; GUILHEM, D. **O que é Bioética**. 1st edition. 7th reprinting. São Paulo: Brasiliense. 2012.

DINIZ, D.; MEDEIROS, M.; MADEIRO, A. Pesquisa Nacional de Aborto 2016. **Ciência & Saúde Coletiva**, v. 22, n. 2, p. 653–660, Feb. 2017.

DINIZ, D. et al. Understanding sexual and reproductive health needs of young women living in Zika affected regions: A qualitative study in northeastern Brazil. **Reproductive Health**, v. 17, n. 1, p. 1–8, 2020.

ECONOMIC COMMISSION FOR LATIN AMERICA AND THE CARIBBEAN (ECLAC). Risks of the COVID-19 pandemic for the exercise of women’s sexual and reproductive rights. **Gender Equality Observatory**, p. 1–13, 2020. Available at: https://repositorio.cepal.org/bitstream/handle/11362/46508/1/S2000905_en.pdf. Accessed: 28 Feb. 2021.

FARMER, Paul. **Pathologies of Power: Health, Human Rights, and the New War on the Poor**. Berkeley: University of California Press, 2005.

FÓRUM BRASILEIRO DE SEGURANÇA PÚBLICA. **Anuário Brasileiro de Segurança Pública 2020**. São Paulo: Ano 14 2020. ISSN 1983-7364. Available at: <https://forumseguranca.org.br/wp-content/uploads/2020/10/anuario-14-2020-v1-interativo.pdf>. Accessed: 25 Feb. 2020.

FOUCAULT, Michel. **Mircofísica do Poder**. 24. ed. Rio de Janeiro: Edições Graal, 1979. Tradução de Roberto Machado.

GONZALEZ, Lélia. **Por um feminismo afro-latino-americano**. Zahar. 2020 Kindle Edition. ISBN 978-65-5782-005-6

GUIMARÃES, Paula. “**Quero voltar logo para jogar futebol**”: a saga de uma criança para fazer o aborto no Brasil. Brazil. Catarinas: Jornalismo com perspectiva de gênero. 17 Aug 2020. Available at: <https://catarinas.info/quero-voltar-logo-para-jogar-futebol-a-saga-de-uma-crianca-para-fazer-o-aborto-no-brasil>. Accessed: 28 Feb. 2021.

GUTTMACHER INSTITUTE. Adding it up. Investing in Sexual and Reproductive Health 2019. p. 56, 2020. Available at: https://www.guttmacher.org/sites/default/files/report_pdf/adding-it-up-investing-in-sexual-reproductive-health-2019.pdf. Accessed: 28 Feb. 2021.

HARMAN, S. Ebola, gender and conspicuously invisible women in global health governance. **Third World Quarterly**, v. 37, n. 3, p. 524–541, 2016

HARRIS, L. H.; SILVERMAN, N. S.; MARSHALL, M. F. The Paradigm of the Paradox: Women, Pregnant Women, and the Unequal Burdens of the Zika Virus Pandemic. **American Journal of Bioethics**, v. 16, n. 5, p. 1–4, 2016.

HAWKES, S.; BUSE, K. Gender and global health: Evidence, policy, and inconvenient truths. **The Lancet**, v. 381, n. 9879, p. 1783–1787, 2013.

HEISE, L. et al. Gender inequality and restrictive gender norms: framing the challenges to health. **The Lancet**, v. 393, n. 10189, p. 2440–2454, 2019.

HILLS, S. L. et al. Transmission of Zika Virus Through Sexual Contact with Travelers to Areas of Ongoing Transmission — Continental United States, 2016. **MMWR. Morbidity and Mortality Weekly Report**, v. 65, n. 8, p. 215–216, 2016.

HOOKS, B. **Feminism is for everybody**: Passionate politics 2nd edition. New York: Routledge. 2015.

JORNAL NACIONAL (org.). **Funcionários do Ministério da Saúde são exonerados por nota sobre atendimento à mulher**. **G1.globo.com**. Rio de Janeiro. 5 jun. 2020. Available at: <https://g1.globo.com/jornal-nacional/noticia/2020/06/05/funcionarios-do-ministerio-da-saude-sao-exonerados-por-nota-sobre-atendimento-a-mulher.ghtml>. Accessed: 5 Mar. 2021.

KASSEBAUM, N. J. et al. Global, regional, and national levels of maternal mortality, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. **The Lancet**, v. 388, n. 10053, p. 1775–1812, 2016.

LANSKY, S. et al. Pesquisa Nascer no Brasil: perfil da mortalidade neonatal e avaliação da assistência à gestante e ao recém-nascido. **Cadernos de Saúde Pública**, v. 30, n. suppl 1, p. S192–S207, Aug. 2014.

LUGONES, M. Toward a Decolonial feminism. **Revista Estudos Feministas**, v. 22, n. 3, p. 935–952, 2014.

LUNA, F. Elucidating the concept of vulnerability: Layers not labels. **IJFAB: International Journal of Feminist Approaches to Bioethics**, v. 2, n. 1, p. 121–139, 2009.

LUNA, F. Identifying and evaluating layers of vulnerability – a way forward. **Developing World Bioethics**, v. 19, n. 2, p. 86–95, 2019.

MARTINES, R. B. et al. Pathology of congenital Zika syndrome in Brazil: a case series. **The Lancet**, v. 388, n. 10047, p. 898–904, 2016.

NAKAMURA-PEREIRA, M. et al. Worldwide maternal deaths due to COVID-19: A brief review. **International Journal of Gynecology and Obstetrics**, v. 151, n. 1, p. 148–150, 2020.

PETERSEN, L. R. et al. Zika Virus. **New England Journal of Medicine**, v. 374, n. 16, p. 1552–1563, 21 Apr. 2016.

POSENATO GARCIA, L. et al. **Violência contra a mulher: feminicídios no Brasil**. Instituto de Pesquisa Econômica Aplicada – Ipea, 2013. Available at: https://www.ipea.gov.br/portal/images/stories/PDFs/130925_sum_estudo_femicidio_leilagarcia.pdf Accessed: 25 Feb. 2021.

REGO, S.; PALÁCIOS, M. Ethics, global health and Zika virus infection: a view from Brazil. **Revista Bioética**, v. 24, n. 3, p. 430–434, 2016.

RIBEIRO, Djamila. **Lugar de fala**. Feminismos Plurais. São Paulo: Jandira. 2020. ISBN:978-85-98349-68-8.

RICE, M. E. et al. Vital Signs: Zika-Associated Birth Defects and Neurodevelopmental Abnormalities Possibly Associated with Congenital Zika Virus Infection — U.S. Territories and Freely Associated States, 2018. **MMWR. Morbidity and Mortality Weekly Report**, v. 67, n. 31, p. 858–867, 10 Aug. 2018.

RICHARDSON, Eugene T. **Epidemic Illusions: on the coloniality of global public health**. Cambridge: The MIT Press, 2020. E-book.

RILEY, T. et al. Estimates of the potential impact of the covid-19 pandemic on sexual and reproductive health in low-and middle-income countries. **International Perspectives on Sexual and Reproductive Health**, v. 46, p. 73–76, 2020.

RONDON, G. Aborto legal em caso de estupro: Portaria 2.282/20 e a necessária independência dos sistemas de saúde e justiça criminal. **Boletim Publicação do Instituto Brasileiro de Ciências Criminais**, n. 336, p. 6–8, Ano 28 2020. ISSN 1676-3661

ROSAS, C. F.; PARO, H. M. DA S. Serviços de Atenção ao Aborto Previsto em Lei: desafios e agenda no Brasil. **Sexuality Policy Watch**, 2021. Available at: https://sxpolitics.org/ptbr/wp-content/uploads/sites/2/2021/02/Texto-Cristiao-e-Helena_Final_26fev-1.pdf. Accessed: 4 Mar. 2021.

ROSS, L. J. Reproductive justice as intersectional feminist activism. **Souls**, v. 19, n. 3, p. 286–314, 2017.

ROSS, L. Understanding Reproductive Justice: Transforming the Pro-Choice Movement. **Off Our Backs**, v. 36, n. 4, p. 14–19, 2006.

ROSS, L. et al. The "Sistersong Collective": Women of color, reproductive health and human rights. **American Journal of Health Studies**, v. 17, n. 2, p. 79, 2001.

ROY, Arundhati. 2004 City of Sydney Peace Prize Lecture. **Peace & The New Corporate Liberation Theology**: CPACS Occasional Paper No. 04/2. Sydney: Arundhati Roy, 3 Nov 2004. 11 p. Available at: https://sydneypeacefoundation.org.au/wp-content/uploads/2012/02/2004-SPP_-Arundhati-Roy.pdf. Accessed: 6 Mar. 2021.

SINGH, Susheela et al. **Abortion worldwide 2017**: uneven progress and unequal Access. New York: Guttmacher Institute, 2017. Available at: https://www.guttmacher.org/sites/default/files/report_pdf/abortion-worldwide-2017.pdf. Accessed 28 Feb. 2021.

SMITH, J. Overcoming the ‘tyranny of the urgent’: integrating gender into disease outbreak preparedness and response. **Gender and Development**, v. 27, n. 2, 2019.

TAKEMOTO, M. L. S. et al. The tragedy of COVID-19 in Brazil: 124 maternal deaths and counting. **International Journal of Gynecology and Obstetrics**, p. 0–3, 2020.

THE WORLD BANK. Maternal mortality ratio (modeled estimate, per 100,000 live births). WHO, UNICEF, UNFPA, World Bank Group, and the United Nations Population Division. Trends in Maternal Mortality: 2000 to 2017. Geneva, **World Health Organization**, 2019. Available at: <https://data.worldbank.org/indicator/SH.STA.MMRT>. Accessed: 25 Feb. 2021.

THEME-FILHA, M. M. et al. Factors associated with unintended pregnancy in Brazil: cross-sectional results from the Birth in Brazil National Survey, 2011/2012. **Reproductive Health**, v. 13, n. S3, p. 118, 17 Oct. 2016.

UNITED NATIONS POPULATION FUND (UNFPA). **Impact of COVID-19 on access to contraceptives in the LAC region. Technical Report**. New York, August. 2020. Available at: https://lac.unfpa.org/sites/default/files/pub-pdf/technical_report_impact_of_covid_19_in_the_access_to_contraceptives_in_lac_1_2.pdf. Accessed: 28 Feb 2021.

VENTURA, Miriam. FUNDO DE POPULAÇÃO DAS NAÇÕES UNIDAS (UNFPA) **Direitos Reprodutivos no Brasil**. 3rd edition. Brasília. 2009. Available at: http://www.unfpa.org.br/Arquivos/direitos_reprodutivos3.pdf. Accessed: 4 Mar. 2021.

WENHAM, C.; SMITH, J.; MORGAN, R. COVID-19: the gendered impacts of the outbreak. **The Lancet**, v. 395, n. 10227, p. 846–848, 2020.

WENHAM, C. et al. Analysing the intersection between health emergencies and abortion during Zika in Brazil, El Salvador and Colombia. **Social Science & Medicine**, v. 270, p. 113671, Jan. 2021.

WENHAM, C. et al. Women are most affected by pandemics — lessons from past outbreaks. **Nature**, v. 583, n. 7815, p. 194–198, 8 Jul. 2020.

WIKAN, N.; SMITH, D. R. Zika virus: History of a newly emerging arbovirus. **The Lancet Infectious Diseases**, v. 16, n. 7, p. e119–e126, 2016.

WORLD HEALTH ORGANIZATION. **WHO statement on the first meeting of the International Health Regulations (2005) (IHR 2005) Emergency Committee on Zika virus and observed increase in neurological disorders and neonatal malformations**. 1 Feb 2016a Available at [https://www.who.int/news-room/detail/01-02-2016-who-statement-on-the-first-meeting-of-the-international-health-regulations-\(2005\)-\(ihr-2005\)-emergency-committee-on-zika-virus-and-observed-increase-in-neurological-disorders-and-neonatal-malformations](https://www.who.int/news-room/detail/01-02-2016-who-statement-on-the-first-meeting-of-the-international-health-regulations-(2005)-(ihr-2005)-emergency-committee-on-zika-virus-and-observed-increase-in-neurological-disorders-and-neonatal-malformations) Accessed: 24 Feb. 2021.

WORLD HEALTH ORGANIZATION. **Zika. Strategic response plan. Revised for July 2016-December 2017**. Geneva. June 2016b, p. 1–50, 2016. Available at: <https://apps.who.int/iris/bitstream/handle/10665/246091/WHO-ZIKV-SRF-16.3-eng.pdf?sequence=1&isAllowed=y>. Accessed: 28 Feb. 2021.

WORLD HEALTH ORGANIZATION. **WHO Director-General's statement on IHR Emergency Committee on Novel Coronavirus (2019-nCoV)**. 30 Jan 2020. Available at: [https://www.who.int/director-general/speeches/detail/who-director-general-s-statement-on-ihr-emergency-committee-on-novel-coronavirus-\(2019-ncov\)](https://www.who.int/director-general/speeches/detail/who-director-general-s-statement-on-ihr-emergency-committee-on-novel-coronavirus-(2019-ncov)). Accessed: 27 Feb. 2021.

WORLD HEALTH ORGANIZATION. **WHO Coronavirus Disease (COVID-19) Dashboard**. 2021a. Available at: <https://covid19.who.int/>. Accessed: 25 Feb. 2021.

WORLD HEALTH ORGANIZATION. **Ebola virus disease**. 23 February 2021b. Available at: <https://www.who.int/news-room/fact-sheets/detail/ebola-virus-disease>. Accessed: 27 Feb. 2021.

WORLD HEALTH ORGANIZATION/PAHO. **Mortalidade materna**. 2018. Available at: [https://www.paho.org/bra/index.php?option=com_content&view=article&id=5741:folha-informativa-mortalidade-materna&Itemid=820#:~:text=Causas da mortalidade materna&text=As principais complicações%2C que representam,normalmente depois do parto\)%3B](https://www.paho.org/bra/index.php?option=com_content&view=article&id=5741:folha-informativa-mortalidade-materna&Itemid=820#:~:text=Causas da mortalidade materna&text=As principais complicações%2C que representam,normalmente depois do parto)%3B). Accessed: 25 Feb. 2021.