ETHICAL AND LEGAL ISSUES IN REPRODUCTIVE HEALTH





Zika virus infection in Brazil and human rights obligations

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Abstract

The February 2016 WHO declaration that congenital Zika virus syndrome constitutes a Public Health Emergency of International Concern reacted to the outbreak of the syndrome in Brazil. Public health emergencies can justify a spectrum of human rights responses, but in Brazil, the emergency exposed prevailing inequities in the national healthcare system. The government's urging to contain the syndrome, which is associated with microcephaly among newborns, is confounded by lack of reproductive health services. Women with low incomes in particular have little access to such health services. The emergency also illuminates the harm of restrictive abortion legislation, and the potential violation of human rights regarding women's health and under the UN Conventions on the Rights of the Child and on the Rights of Persons with Disabilities. Suggestions have been proposed by which the government can remedy the widespread healthcare inequities among the national population that are instructive for other countries where congenital Zika virus syndrome is prevalent.

KEYWORDS

Children's rights; Congenital Zika virus syndrome; Disability rights; Human rights; Public health; Women's rights; Zika infection

| INTRODUCTION

On February 1, 2016, acting under the International Health Regulations (2005) authorized according to the WHO Constitution, WHO declared spread of the infectious Zika virus to constitute a Public Health Emergency of International Concern, associated with the number of children born with congenital Zika virus syndrome to mothers infected with the Zika virus. This syndrome includes a wide range of malformations, including microcephaly, which can incur moderate-tosevere neurological disabilities. Early in February 2016, Zika virus was recorded to be circulating in 33 countries¹-mainly in the Americas and the Caribbean—and further spread of the infection is anticipated.²

Zika is not necessarily new to hot, humid areas, particularly those with poor environmental infrastructure and stagnant water, a mosquito breeding ground. The Zika flavivirus is transmitted by mosquitoes of the Aedes family-notably Aedes aegypti-and was first identified in human beings in the Zika rainforest of Uganda in 1952, with subsequent outbreaks found in Africa, Asia, the Pacific, and the

Americas.³ Attempts to suppress viral infections transmitted by Aedes aegypti in the Americas go back more than a century. 4 Symptoms of Zika virus infection are often mild (e.g. low-grade fever, rashes, and itching for 2-7 days), are self-limiting, and are usually treated, if at all, on an outpatient basis. 5 However, Guillain-Barré syndrome—a considerably more serious respiratory and paralytic effect of infection⁶—has been associated with the Zika virus.⁷

The increasing incidence of Zika virus infection⁸ has caused alarm in Brazil, where infection is concentrated mainly among young black and brown women with low incomes living in the country's least economically developed regions,9 including heavily populated urban regions and remote backland areas. The high number of cases in the country-which triggered international concern leading to WHO's declaration of a Public Health Emergency of International Concern¹⁰ has implications for women's health, as well as the immediate and long-term welfare of children they conceive. 11 In March 2016, the Brazilian Ministry of Health published guidelines providing recommendations for provision of care in the contexts of family planning through

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prenatal and infant care. However, the guidelines fail to acknowledge the practical difficulties that many Brazilian women (especially disadvantaged women with low incomes in less-developed regions) face in gaining information about, and access to, effective contraceptive means, and ignore the public health menace of unsafe abortion 12 associated with the country's exceptionally restrictive and vigorously enforced criminal abortion law. 13 Challenges of implementing the Ministry's recommendation and suggestion go far beyond the medical, 14 and raise critical issues with a country's human rights and legal obligations to achieve health equity that have been filed in a complaint before the Supreme Federal Court of Brazil. 15

2 | PUBLIC HEALTH EMERGENCY RESPONSES AND HUMAN RIGHTS

Claims to human rights can be traced back to the French Revolution and Thomas Paine's 1791 publication *The Rights of Man*, and Mary Wollstonecraft's less-cited A Vindication of the Rights of Woman of 1792. The modern foundation of legal human rights claims, however, lies in international responses to outrages against individuals and populations leading to and during the Second World War, and a series of international human rights conventions agreed under the auspices of the United Nations Organization (the UN), which was established in 1945. Originating in protection of individuals' rights against governments including military authorities, modern claims include entitlements of populations and subgroups, including those alienated from wider populations within which they suffer unjust deprivations on grounds such as low income, education, and access to equal opportunities.

Clinical health measures are pursued at the individual level, typified in the doctor-patient relationship, but public health is pursued (or neglected) at the governmental level. Responses to public health emergencies are the responsibility of governments, at best with collaboration from private sector agencies and individuals, but if necessary in opposition to their pursuit of private group and individual interests, such as through governmental mandates for compulsory vaccination and requisition of private property. Public health ethics differ from clinical bioethics-which are centered on personal autonomy and interests-so much that leading authorities on public health ethics concluded a pioneering essay on the genesis of public health ethics by observing that "As we commence the process of shaping an ethics of public health, it is clear that bioethics is the wrong place to start." ¹⁶ Similarly, public health legislation that satisfies human rights claims differs in some regards from private legislation, which can address such matters as private contracts, private injuries, and property ownership and transfer, because it requires employment of governmental resources and restraints that can contradict influential religious and other institutional preferences, such as through relaxation or suspension of restrictive abortion laws.

The complaint of inadequate governmental responses to the Zika emergency filed before the Supreme Federal Court of Brazil links claims to women's human rights to reproductive health services and choices with human rights claims by individuals caring for children affected by neurological and associated disabilities, and with claims on behalf of disabled children themselves. The complainants have explained: "we are arguing that women should have access to information and comprehensive prenatal care, including, if infected, the right to terminate a pregnancy. We also argue for strengthened social protection and policies for women and families with affected children."¹⁷

Human rights of the general population are asserted to be violated by inadequately effective public education campaigns about transmission of Zika virus, including sexual transmission, and about availability of contraceptive methods through the public health system. Development is urged of family planning policies and reproductive health care in accordance with international standards and medical consensus on best-available contraceptive methods, including long-acting reversible methods. For infected pregnant women experiencing intense, health-impairing anxiety about their future and that of their children, the legal right to pregnancy termination is sought.

The complaint similarly addresses governmental failure to provide adequate financial and related support, including paid maternity leave and the constitutional right to a cash benefit for people with disabilities, and requires practical means of access to early stimulation services for children with congenital Zika virus syndrome. Underpinning the legal proceeding are claims that Ministry of Health recommendations alone on pregnancy avoidance fall short of governmental human rights obligations to protection of health, and that greater protection is required to prevent discrimination on grounds of disability, covering not only Zika-related physical and mental disability, but also that due to disadvantages related to socioeconomics and race, particularly skin color. Evidence shows that 80% of neonates with congenital Zika virus syndrome are born to black or brown mothers.¹⁸ It has been observed that "The epidemic mirrors the social inequality of Brazilian society."

3 | WOMEN'S SEXUAL AND REPRODUCTIVE HEALTH

Governments reacting to emergencies, both real and perceived, are liable to discount the human rights obligations they have voluntarily assumed under international human rights covenants. In the health context, for instance, involuntary vaccination, contact tracing and mandatory disease reporting to government agencies in breach of confidentiality, and quarantine detention of individuals exposed to infection all affect the balance between protection of individual human rights and pursuit of the public good. By contrast, governments might invoke scientific uncertainties to decline to act in the face of an apparent menace for fear of being accused of acting precipitately without sufficient evidence. Responses to Zika virus infection, which has proven injurious and even catastrophic in regions of Brazil, have been beset by scientific uncertainty of the effects of the virus, 20 the extent of the resulting damage, 21 and the most suitable means of containment.²² However, the precautionary principle, which emerged to address profound risks to public and environmental health in the absence of a scientific consensus, supports preventive interventions to

forestall potential harms, such as physical and mental health injuries, and unjust social discrimination.

Denial and obstruction of sexual and reproductive health services, particularly to deprived and dependent populations, can constitute human rights violations. The Committee on Economic, Social and Cultural Rights, which monitors compliance with the UN's International Covenant on Economic, Social and Cultural Rights, records that "Sexual health, as defined by WHO, is a state of physical, emotional, mental and social well-being in relation to sexuality"^{23 (para. 6)}. Reproductive health was defined in the Programme of Action resulting from the 1994 UN International Conference on Population and Development to include individuals' rights to "appropriate health care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant."24 The focus of the state duty to satisfy this right extends beyond avoidance of preventable maternal and infant mortality and morbidity, to include appropriate measures to prevent the physical and mental health effects of Zika virus on women and their infants.

The incidence of Zika infection in Brazil appears to conform to the common experience of infectious disease epidemics, raising concerns of social equity and justice achievable through law applicable beyond any single country. It has been observed that "because infectious diseases primarily affect the poor and disempowered, the topic of infectious disease is closely connected to the topic of justice. Malnutrition, dirty water, crowded living conditions, bad working conditions, poor education, lack of sanitation and hygiene, and lack of decent health-care provision all increase chances that those who suffer from poverty will also suffer from infectious disease."25 This observation from a global perspective is fully vindicated in the microcosm of Brazil, 19 not only in the demographic epicenter of Zika infection-Rio de Janeiro-but also in outlying areas. ⁹ The government is accordingly called upon to take necessary action, under the human rights obligations it has voluntarily undertaken under its own constitution and international covenants to satisfy a spectrum of legal rights to reproductive health.

Under the International Covenant on Economic, Social and Cultural Rights, the Committee on Economic, Social and Cultural Rights has explained that, like the right to health more generally, "the right to sexual and reproductive health entails a set of freedoms and entitlements. The freedoms include the right to make free and responsible decisions and choices, free of violence, coercion and discrimination, over matters concerning one's body and sexual and reproductive health. The entitlements include unhindered access to a whole range of health facilities, goods, services and information, which ensure all people full enjoyment of the right to sexual and reproductive health under article 12 of the Covenant" (para. 5). Article 12 recognizes "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." Relevant legal rights can be ordered in different priorities, but include rights to health care equally with others in the community, rights to be free from inhuman and degrading treatment or punishment including freedom from neglect of indicated treatment, and rights to special protection and assistance for pregnant women before, during, and after childbirth, for children with disabilities, and for their families.

4 | REPRODUCTIVE HEALTH RIGHTS

In principle, reproductive health rights should be afforded to both control and promote reproduction, but because the Brazilian Ministry of Health has issued its guidelines recommending that women at risk of Zika infection avoid pregnancy, only the former are relevant here. Brazilian law does not bar women's resort to contraception, but falls short of providing access to marginalized women. Under Article 12(1) of the UN human rights Convention on the Elimination of All Forms of Discrimination against Women, states undertake "to ensure...access to health care services, including those related to family planning," and under Article 12(2) "to ensure...appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary."26 Because "until now, there have been no reports [in Brazil] of affluent women giving birth to babies with Zika-related neurological disorders," the case filed before the federal Supreme Court argues for "strengthened social protection and policies for women and families...including immediate cash transfer benefits"¹⁷ to equip impoverished women to obtain family planning and related services, including costs of travel to service providers.

Ministry of Health policy appears to be directed to reduction of births of newborns with congenital Zika syndrome. It is therefore perverse that women and health service providers who act consistently with this public purpose face fierce prosecution and punishment if they attempt to terminate affected pregnancies. In 2012, the Supreme Federal Court of Brazil ruled the prohibitive criminal law on abortion inapplicable to anencephalic pregnancies, 27 in which affected newborns have no prospect of survival. Before the 2012 ruling, in a case seeking judicial approval of such pregnancy termination involving the second pregnancy of a 19-year-old woman named Gabriela, proceedings were so delayed that "[f]ive days before the Justices were set to hear her case, Gabriela went into labor and delivered a full-term anencephalic child...who was pronounced dead seven minutes after birth."²⁷ Nevertheless, "[a]n organized Catholic anti-abortion group, galvanized to stop the medical procedure from taking place, fought against its authorization all the way to the higher federal court."27 It could be anticipated that the argument that human rights obligations require limitation or suspension of the criminal law prohibiting abortion will attract the same opposition in court, and face the same lack of political support.

Politicians' indifference to, if not sympathy with religious opposition to, lawful, safe abortion is liable to remain while they and their families are unaffected. Disadvantaged women with low incomes have to face hazardous pregnancies and legal constraints on termination, whereas "middle- and upper-class women, who have the means to seek a private clinic, can count on a wide net of abortion and post-abortion services—clandestine in many cases but also a few that are somewhat more mainstream—usually undisturbed by the legal prohibition or enforcement agencies....This disparity is a key element in

keeping the widespread opposition to abortion intact, since a change in the legislation is much less important for the most politically and economically influential segments of society given that they do, to a large extent, get the appropriate abortion services they need...and avoid any negative consequences to their social, moral and religious standing."²⁷

The case filed before the Supreme Federal Court can serve to alert influential segments of Brazilian society to economic and related implications of accommodating sizeable numbers of disabled fellow citizens, and to increased instances of maternal deaths and disabilities due to unsafe abortion. Unsafe, invariably unlawful, abortion is a common practice among Brazilian women. By the age of 40 years, one in five women has experienced at least one abortion.²⁸ Unsafe abortion has been among the top five causes of maternal death in Brazil, ²⁹ and the prospect of a Zika-induced increase could persuade public and judicial opinion to accommodate legal reform favoring safe, lawful procedures. The Supreme Federal Court has the opportunity to redress a pervasive socioeconomic inequity. Such inequity has transcended decades and continents, and affords more affluent women de facto immunity from prohibitive abortion laws but burdens women of low incomes with aggravated poverty, children they cannot support, or the risks of unsafe abortion causing them injury or death.³⁰

5 | CHILDREN'S SPECIAL NEEDS

Two of the more recently implemented UN international human rights covenants coincide to condition states' obligations to serve the special needs of children with congenital Zika virus syndrome, namely the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD), both of which Brazil has ratified. The CRC applies to "every human being below the age of eighteen years unless under the law applicable to the child majority is attained earlier" (Art. 1), meaning that mothers younger than 18 years would be "children" unless by local law they reach majority on earlier marriage or childbirth. From a child's birth, the state undertakes to respect and ensure his or her rights "without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, color, sex...national, ethnic or social origin, property, disability, birth or other status" (Art. 2(1)), and to "ensure to the maximum extent possible the survival and development of the child" (Art. 6(2)).

Linkage to the CRPD is made through CRC article 23, which requires recognition that a mentally or physically disabled child should enjoy a full and decent life in conditions of dignity, self-reliance, and active community participation. Under article 23(2), the state should "recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance...appropriate to the child's condition and to the circumstances of the parents or others caring for the child." By article 23(3), such assistance "shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child

has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development...." Limitations are that required assistance is that "for which application is made" (Art. 23(2)), which requires a caregiver to have or acquire the information, capacity including literacy, and persistence to make an application, and that administrative determinations of need for, and appropriateness of, assistance could reflect the political indifference to the claims of poor and disadvantaged populations observed above.

It is reasonable that the human rights obligation to render assistance to and for the child in need of special care should be "subject to available resources" (Art 23(2)). It is not assured, however, that without intervention such as a high-level judicial directive might provide, the needs of Zika-affected children and their families will be a higher priority in public resource allocation than healthcare provision for the populations in which Zika infection is most prevalent has been in the past in Brazil. A measure of provision of special care could be satisfaction of a child's right to general health care, which under CRC article 24(1) is "to the enjoyment of the highest attainable standard of health." To implement this right, the state is required, among other services, to "diminish infant and child mortality...ensure the provision of necessary medical assistance and health care...combat disease and malnutrition...through the provision of adequate nutritious foods and clean drinking water...ensure appropriate pre-natal and post-natal health care for mothers...[and] develop preventive health care, guidance for parents and family planning education and services" (Art. 24(2)).

The CRPD explains that its purpose is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities," who "include those who have long-term physical, mental, intellectual or sensory impairments which...may hinder their full and effective participation in society on an equal basis with others" (Art. 1). The word "include" shows that the explanation of "disabilities" is not exhaustive. The US Supreme Court, for instance, has ruled that an individual's refusal to treat an asymptomatic HIV carrier "disabled" the carrier from "participation in society on an equal basis with others."31 The CRPD would accordingly prohibit discrimination against not only individuals with congenital Zika virus syndrome, but also people with Zika virus infection in whose bodies persistence of the virus⁵ would satisfy the criterion of them having a "long-term" impairment. It has been suggested, for instance that "use of condoms might...need to continue to be used for 4 months to prevent sexual transmission" of the Zika virus. 32

In the CRPD, "discrimination" has an expansive definition. It means "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation" (Art. 2). This definition affords the CRPD comprehensive scope in condemning any and all forms of discrimination on grounds of disability, but it gives particular attention to women and children with disabilities. A state "shall take all

appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms" provided in the Convention (Art. 6(2)). Women's rights are of special importance, of course, when they are the primary guardians of children. Similarly, states shall "ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children" (Art. 7(1)).

Reproductive health care of individuals disabled by Zika infection is addressed in provisions on respect for the home and family, and on health. The state shall ensure that their rights "to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and [that] the means necessary to enable them to exercise these rights are provided" (Art. 23(1)). Similarly, the state shall provide them with "the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes," and shall provide such services "as close as possible to people's own communities, including in rural areas" (Art. 25). Children are protected when women have appropriate means of birth spacing, for instance.

The financial costs any government would incur to satisfy legal obligations assumed under CRC and CRPD might make a cynical economic case to wealthy tax-payers and, for instance, international funding agencies and private charitable health service foundations in favor of liberal family planning and abortion access for low-income populations that conscientious policy advocates might be embarrassed to advance.

6 | HEALTH EQUITY

Underpinning ethical and legal concerns regarding congenital Zika virus syndrome due to maternal Zika infection and human rights obligations in Brazil (and frequently elsewhere), and the case filed before the Supreme Federal Court of Brazil, are inequitable disparities between health status and access to healthcare services among different sectors of the population. Such concerns are not peculiar to Zika, 33 but have special salience in Brazil where social inequities in access to safe reproductive health services including abortion²⁷ are so acute. Health inequities commonly refer to "differences in health that are not only unnecessary and avoidable, but in addition unfair and unjust,"34 now understood as health disparities that are unjust precisely because they are avoidable and therefore unnecessary. 33 Family planning strategies can avoid births of compromised newborns, but avoidance of Zika infection itself remains a work in progress, for instance through control of mosquitoes or their genetic manipulation, 35 or development of a vaccine²² or suitable anti-viral medication.³⁶

The theme of health equity, incorporating evolving understanding of the social determinants of health, has generated a vast, sophisticated modern literature,³⁷ but a generalized conclusion associating poor health with individual, family, and community poverty is clearly

buttressed by evidence from Brazil. It is observed that "The Zika epidemic has given Brazil a unique opportunity to look at inequality and reproductive rights, and to change how the country treats women. Asking women to avoid pregnancy without offering the necessary information, education, contraceptives or access to abortion is not a reasonable health policy." It is explained above that this failure also violates ethical and legal human rights obligations. An argument is mounting that a state's support, conditioning, or tolerance of health inequity among its population is itself a human rights violation. This claim transcends issues of clinical management of infection and needs of individual affected newborns, and locates concerns in the realm of justice in public health.

CONFLICT OF INTEREST

The authors have no conflicts of interest.

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