Engaging Human Rights in the Response to the Evolving Zika Virus Epidemic

In late 2015, an increase in the number of infants born with microcephaly in poor communities in northeast Brazil prompted investigation of antenatal Zika infection as the cause. Zika now circulates in 69 countries, and has affected pregnancies of women in 29 countries.

Public health officials, policymakers, and international organizations are considering interventions to address health consequences of the Zika epidemic. To date, public health responses have focused on mosquito vector eradication, sexual and reproductive health services, knowledge and technology including diagnostic test and vaccine development, and health system preparedness.

We summarize responses to date and apply human rights and related principles including nondiscrimination, participation, the legal and policy context, and accountability to identify shortcomings and to offer suggestions for more equitable, effective, and sustainable Zika responses. (*Am J Public Health.* 2017;107:525–531. doi:10.2105/AJPH.2017.303658)

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On February 1, 2016, the World Health Organization (WHO) declared a Public Health Emergency of International Concern in response to a cluster of microcephaly (restricted fetal brain and skull growth) and neurological disorders likely associated with Zika virus. Although previous Zika outbreaks were considered benign, a dramatic rise in babies born with microcephaly in poor communities in northeast Brazil prompted investigation of infectious etiologies. By April 2016, scientists concluded that antenatal Zika infection causes miscarriage, stillbirth, and a range of neurological malformations including microcephaly, but also motor, ocular, and auditory changes.[1–3] At that time, infection was thought to be transmissible only via mosquitoes, but sexual transmission was detected shortly thereafter.[4] Since October 2015, 69 countries and territories have reported evidence of local Zika transmission in the Americas, Caribbean, Asia, and the Pacific. Women in 29 countries have had pregnancies affected by congenital Zika infection.[5]

Despite all that has been learned about Zika, important unknowns remain. Key knowledge gaps include the absolute risk of harm from perinatal infection at each gestational age (although several recent studies help to narrow this gap[6]), the spectrum of health consequences comprising congenital Zika syndrome and the period of time over which they might manifest, the length of time after maternal infection during which a fetus would still be at risk, and the optimal time for women in Zika-affected countries to conceive to reduce the likelihood of congenital infection. Additional unknowns concern the neurodevelopmental risks of Zika infection among breastfeeding infants and whether previous Zika infection confers immunity for future pregnancies. At this time, there is no rapid diagnostic test for Zika, no treatment for pregnant women infected by Zika, and no vaccine to prevent perinatal infection.

Recently, WHO reclassified Zika as a longer-term program of work rather than a Public Health Emergency of International Concern, anticipating long-standing consequences. Indeed, public health officials, policymakers, and international organizations are carefully considering how best to address short-, medium-, and long-term health consequences of Zika virus. Misguided responses could undermine the ability of communities and governments to adequately address the health and social impacts of Zika, further jeopardize the emotional and physical health of vulnerable women and men, and misdirect research and development (R&D) efforts. As has been demonstrated in other epidemics, including malaria and HIV, engaging human rights supports equitable responses that prioritize disproportionately affected, marginalized communities and act on underlying determinants of health, which are ultimately more effective and sustainable.[7] Drawing on these lessons, we describe 4 categories of responses to Zika, enumerate the most relevant human rights principles, and apply these principles to identify shortcomings of current approaches and suggest ways forward.

RESPONSES TO THE ZIKA EPIDEMIC

When the epidemic of infants born with microcephaly in Brazil was identified, Zika virus was already spreading across the

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This article was accepted January 2, 2017.
doi: 10.2105/AJPH.2017.303658

Americas, where there is no pre-existing population immunity. As countries began to respond, any discussion of human rights centered on sexual and reproductive rights.[8] Human rights principles are relevant to all facets of the response, however, including (1) vector control to limit the spread of Zika via mosquitoes, (2) sexual and reproductive health interventions, (3) generating knowledge and technology including diagnostic tests and a vaccine, and (4) health system preparedness to address the longitudinal needs of families affected by Zika. Each category is a crucial component of a comprehensive response to the epidemic, although different communities may prioritize one or another aspect given existing resources.

Vector control, aimed at reducing fetal exposure to the virus by controlling mosquito populations, is recommended by WHO, the Pan-American Health Organization, and the Centers for Disease Control and Prevention (CDC).[9] Some of the earliest responses in Brazil, for example, entailed destroying mosquito reservoirs while also advising pregnant women to avoid mosquito bites via protective clothing, bed nets, mesh screens, and insect repellent.[10] Reproductive-age or pregnant women in other countries were advised to avoid travel to Zika-endemic areas.[11] Some communities additionally sprayed pesticides, and others considered novel biological mosquito-control strategies.

Another category of responses to Zika relates to sexual and reproductive health—making recommendations about sexual activity and scaling up access to pertinent services. When sexual transmission of Zika was confirmed, the CDC advised women to avoid unprotected sexual intercourse with male partners who live in or had traveled to Zika-endemic areas.[12] Perhaps drawing the most intense media attention, public health officials in Brazil, Colombia, Ecuador, El Salvador, and Jamaica advised women to delay childbearing—for up to 2 years in the case of El Salvador.[13] Some, including the Office of the High Commissioner of Human Rights and women's rights advocates responded by calling for expanded access to abortion services.[8] Officials in Colombia moved to consider Zika an acceptable rationale for legal abortion under its 2006 law,[14] but no other countries have followed suit.

A third group of responses relates to building knowledge and technology development: aggressively researching the pathophysiology and health impacts of Zika infection; funding and accelerating research into diagnostic tests, treatments, and vaccines; and making the most up-to-date information publicly available. Although the US National Institutes of Health called for "all hands on deck" for Zika vaccine development in January, President Barack Obama's request to Congress to fund Zika-related research and response was not approved for 9 months. For its part, WHO led on delineating research priorities, identifying current products in the Zika pipeline, and holding public consultations on R&D readiness for epidemics.[15] In particular, the Statement on Data Sharing in Public Health Emergencies represents a commitment by academic journals and institutions to make content concerning the Zika epidemic open access.[16]

The final group of responses relates to health system preparedness and (re)organization to meet longitudinal care needs of Zika. Although efforts are ongoing to strengthen laboratory and surveillance networks in several countries in the Americas,[9] relatively less attention has been paid to health system structure, workforce, and financing. To our knowledge, even where sexual and reproductive health services have been scaled up, such as Puerto Rico,[17] there is no widespread scale up of physical therapy or other relevant services, and few governments have made public how they are accounting for Zika in their health planning and budgeting.

Before exploring the ways in which attention to human rights might enhance these responses, we enumerate the relevant human rights principles.

PERTINENT HUMAN RIGHTS PRINCIPLES

Human rights, as used here, encompass those indivisible, interrelated, and universal freedoms guaranteed to individuals and groups by international law. After ratifying human rights treaties, governments have responsibility for respecting, protecting, and fulfilling those rights through transparent steps that may be progressively realized as resources allow. These responsibilities extend to parties who work for and with the state, including program implementers and health care workers.[18] Most relevant to Zika are the rights to health and information, but the principles of nondiscrimination, participation, and accountability are additionally pertinent. Because of the ways in which the legal and policy environment can support or jeopardize the realization of human rights, we include this as a related principle relevant for every category of response to Zika. The box on the next page describes the rights and principles most relevant to the Zika epidemic.

In the following paragraphs, we provide contextual information, apply human rights principles to identify shortcomings in ongoing responses, and suggest ways in which attention to rights may result in more equitable and, therefore, more effective and sustainable responses. We also highlight relevant laws or policies that merit particular consideration in each category of response, as these can hinder or facilitate the success of Zika response efforts. Accountability is discussed separately.

Vector Control

For many people, mosquitoes are ubiquitous and unavoidable. Because it requires little stagnant water to reproduce, *Aedes aegypti*, the mosquito that transmits both dengue and Zika, is extremely difficult and costly to control. *Aedes* is strongly associated with poverty: garbage dumping in overcrowded areas provides ample breeding grounds, and mosquitoes may proliferate near homes without mesh screens.[21] In this way, poverty determines the populations at highest risk for infection. Human rights and related principles offer at least 3 recommendations to enhance the success of vector-control efforts.

First, we consider nondiscrimination. Nondiscrimination questions how local or national responses meet the needs of those populations most affected by Zika. Rather than proceeding with conventional mosquito-control strategies that are short-lived and ineffective against *Aedes* even in

HUMAN RIGHTS AND PRINCIPLES MOST RELEVANT TO THE ZIKA EPIDEMIC

Right to health

The right of everyone to the enjoyment of the highest attainable standard of physical and mental health includes the availability, accessibility, acceptability, and quality of goods and services. That is, health services have to be *available* in sufficient quantity; economically and physically *accessible* to everyone without discrimination, including information about the health service(s); respectful of medical ethics and culturally appropriate such that they are *acceptable* to users; scientifically and medically appropriate; and of good *quality*.

This "[extends] to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health."[19(p3)]

Right to freedom of information

The right to seek, receive, and impart information and ideas of all kinds; states have an obligation to ensure access to unbiased, comprehensive, and scientifically accurate information.[20]

Nondiscrimination

International human rights law prohibits any discrimination in access to health care and the underlying determinants of health on the basis of "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health."[19(p7)]

Participation

The ability of individuals and groups affected by a policy, program, or strategy to participate in decision-making around its design, implementation, and evaluation.[19] Participation increases the likelihood that a policy or program is responsive to the needs of users or recipients.

Legal and policy context

The legal and policy context—including health policies and those considered external to the health sector per se—can support or jeopardize population health as well as the performance of health systems. For example, laws might prevent certain services from being offered, limit their accessibility by vulnerable groups, or, alternatively, mandate their provision.

Accountability

Governments have responsibility to prevent violations from occurring, to hold rights violators to account, and to have mechanisms in place to allow challenge and redress if violations are alleged to have occurred. Accountability mechanisms should exist at local, national, regional, and global levels to monitor the compliance of governments with their human rights obligations. Individuals or groups of people who experience rights violations should have access to effective remedies and adequate reparation at all levels.

well-resourced communities,[22] Zika-related vector control should be explicitly designed with attention to the most-at-need populations. This could entail engaging the sanitation sector to target breeding grounds or testing novel technologies such as genetically modified mosquitoes—the latter being explored in Florida—that might more effectively and sustainably disrupt Zika transmission in resource-poor areas where reservoirs cannot be destroyed.

Second, the participation of affected communities may be particularly important. Communities hardest hit by Zika might understandably be skeptical about widespread use of concentrated pesticides and genetically modified or bacteria-laden mosquitoes given the communities' histories of being relatively neglected, discriminated against, or lied to by public officials. Dialogue with affected communities would elucidate their needs and fears, encourage leadership and solutions from within the community, and cultivate buy-in for mutually acceptable plans. Experience from Kenya, for example, credits social mobilization and participation with reducing malaria cases among children.[23]

Finally, in keeping with the right to health, action on the underlying determinants that define one's relative risk for and resilience to Zika is needed. That is, a more sustainable response to Zika would include strategies that address the structural drivers of poverty itself, including access to clean water, sanitation, housing, and education. Here, analysis of the legal and policy context should focus on laws that render rural, low-income, and uneducated women most vulnerable to antenatal Zika infection, such as housing policies that simultaneously concentrate poverty and health risks in the same spaces.[24] Policymakers should pursue proven poverty-reduction strategies, and these are also targets for civil society advocacy. In addition, policies to slow climate change will have durable impact in shaping the severity and reach of this and future mosquito-borne epidemics.

Sexual and Reproductive Health

Zika is a reminder that women in Latin America and the Caribbean have limited access to contraception, as roughly 56% of pregnancies are unplanned.[25] Access to scientifically accurate, comprehensive, and timely information is fundamental for making choices about whether to pursue, avoid, or continue a pregnancy. The right to health and the right to freedom of information suggest the right for

pregnant women and their partners to have access to the most up-to-date information on the health consequences of Zika infection. Although information arrived too late for a "first generation"[26] of women with pregnancies affected by Zika, women currently making reproductive decisions must have access to information on the efficacy, correct use, and side effects of family planning methods; sexual transmission of Zika and its prevention; timely antenatal Zika diagnosis; accurate antenatal testing; and diagnosis of neurological malformations as well as confidential counseling.[27]

The right to health has long been understood to include the right to choose "the number, spacing and timing of their children."[28(p60)] A human rights–based response to Zika thus necessarily entails universal access to effective female- and male-controlled contraception including emergency contraception. The hard-learned lesson from the HIV epidemic that condoms, not abstinence, reduce sexual transmission of viral infections is salient here.[29] Furthermore, attention to the principle of nondiscrimination would ensure that the full range of sexual and reproductive health services be specifically made available to those women with the least access. A range of strategies including mobile service delivery, expanded availability of emergency contraception, rural health worker deployment, community-based health promotion, and subsidized contraception might enhance access to sexual and reproductive health services for the most vulnerable women. Moreover, gender-based discrimination has been inadequately addressed in responses to Zika. A human rights–based response would extend work to redress the structural, economic, and social manifestations of gender-based discrimination that limit access to both information and services.[30]

Recommendations that women avoid pregnancy during the Zika outbreak have been extensively critiqued: asking women to delay childbearing when their reality is characterized by inconsistent access to contraception, pervasive sexual violence, and allegiance to Catholic and Evangelical churches is at best unrealistic and, at worst, irresponsible.[8,31,32] In the context of a sexually transmitted infectious outbreak that causes miscarriage, stillbirth, and neurological malformations—and, importantly, when women cannot judge the risk of harm to their fetuses—pregnant women will seek abortion even if illegal.[33] Given persistent unknowns about the full spectrum of risks of antenatal Zika infection, pregnant women in Zika-affected areas need access to options counseling as well as safe abortion services.

When women delay seeking care after clandestine abortion for fear of criminalization or incarceration, maternal morbidity and mortality are even higher. Hence, realizing the right to health also necessitates reducing harm from unsafe abortion and delayed postabortion care. This entails providing greater access to safe abortion and postabortion care as well as reversing abortion restrictions. Indeed, personal choices become political when individuals are denied the legal right to make—or act on—their reproductive choices.[31] The courts can be an important location of challenge to abortion laws even with conservative governments. Litigation strategies might emulate Colombia in expanding health exceptions for abortion on the basis of emotional distress and psychological harm endured by pregnant women with Zika. Alternatively, building on the Brazilian court's 2010 ruling that women with anencephalic fetuses may legally terminate a pregnancy, a recent petition argues for the right to legal abortion in the context of Zika.[34]

Recognizing that legalizing abortion is not politically feasible for many governments—one bill introduced to the Brazilian National Congress sought to penalize abortion because of Zika with up to 15 years in prison[35]—policies that may, at least, reduce women's physical and psychological suffering are needed. For example, decriminalizing providers who perform abortions could make safe procedures more available and accessible. Lastly, Zika's spread from Florida to Texas, where legislation repeatedly attempts to limit access to abortion, may prove a useful entry point for advocacy campaigns and legal challenges to contest abortion restrictions in the United States.

Knowledge and Technology

Confirmation that antenatal Zika infection causes neurological malformations cemented global demand for accurate diagnostic tests and a vaccine. The Food and Drug Administration approved a polymerase chain reaction–based diagnostic test for commercial use in the United States, but women and men in Latin America may struggle to access these tests. At the same time, pharmaceutical companies are racing toward a vaccine.[36]

To meet the obligations of the right to health, the right to freedom of information and nondiscrimination, rapid diagnostic tests, therapeutics, and vaccines (as they are developed) must be available and accessible to all women and men, in particular those who are most vulnerable to the harms of Zika—not just those in high-income countries. Decades of fighting for access to antiretroviral drugs for HIV have shown that equitable distribution is possible and effective. The struggle for antiretroviral medicines undoubtedly turned global attention to the incoherence between human rights and public health on one hand and intellectual property and trade agreements on the other, the latter facilitating high drug prices and high profits for the pharmaceutical industry at the expense of human lives. Global activism for access to medicines has generated growing recognition that high prices should not impede access to health technologies. Despite significant public investments in R&D, however, prohibitive pricing remains the single largest barrier to novel technologies. Attention to the legal and policy context not only identifies the need for continued advocacy to ensure public return on public research investments, including through the use of World Trade Organization Agreement on Trade-Related Aspects of Intellectual Property flexibilities, but also suggests legal remedies such as broadening the judicialization of access to medicines[37] to include Zika-related technologies. Still, a rights-based response goes further: limited availability of diagnostic tests (and, later, treatments and a vaccine) in the hardest-hit communities raises the specter of discrimination in the functionality of existing R&D mechanisms.

Existing R&D incentives are ill-suited to respond to public health needs, in particular for vulnerable populations and new

epidemics. When industry interest drives innovation, a vaccine's development may depend more on potential profit than on public health need. For example, some have argued that a vaccine should be developed to protect against both dengue and Zika. Dengue, however, lacks the projected profitability from prospective markets in high-income countries that is likely driving pharmaceutical companies to develop a Zika vaccine.[36] The ability of potential markets to drive R&D more effectively than health priorities clashes with both public health and human rights principles. Efforts to de-link R&D financing and priority setting from profit margins would promote equitable availability of new health technologies and shift responsibility and accountability for innovation and access to medical technologies from the private sector to governments and international agencies.

Analogously, researchers are incentivized to hold discoveries for publication to compete for limited research funding rather than promptly share data and conclusions. In the context of a public health emergency such as Zika, however, the lack of a public platform for data sharing hampers scientific discovery and may interfere with the response, as was the case for Ebola.[16] The rights to health and to freedom of information, along with the principle of nondiscrimination, reinforce the need for an open data-sharing platform as a global public good.

Health System Preparedness

Although the severity of Zika congenital syndrome varies, the majority of affected children require specialized medical and social services that far surpass routine services in public health systems. They may require, for example, longitudinal specialist care, physical and occupational therapy, or stays in long-term care facilities. Even in Zika-affected countries with well-functioning health systems, unanticipated numbers of children with congenital Zika syndrome will likely overwhelm capacity. Although WHO has worked with member states to strengthen surveillance and laboratory networks and to augment antenatal services, the capacity of health systems to address the myriad needs of families affected by Zika has received relatively less attention.

The rights to health and freedom of information, along with the principles of non-discrimination and participation, reveal key ways in which health system responses to Zika can be made more equitable and, therefore, more effective and sustainable. Beyond sexual and reproductive health, Zika-related services must include specialized medical and physical care for infants born with neurological malformations as well as psychological support for families affected by Zika. Chronic care services are costly and must be budgeted for in health financing processes. Recalling that families seeking Zika-related services will be concentrated in the areas where health care providers are likely in shortest supply, a rights-based approach recognizes that health systems may need to divert staff and resources to the geographical areas with greatest Zika prevalence. Participation of pregnant or reproductive-age women as well as women with children affected by Zika could help identify health services and technologies to prioritize for scale up. Similarly, children affected by Zika should also be longitudinally engaged in health planning to foster respect for their rights and dignity.[27] Finally, those charged with planning health services should address the potential harms of scaling up services related to Zika at the expense or exclusion of primary care services for marginalized communities. Analysis of the constellation of laws related to the organization and financing of individual health systems—and the way(s) in which they might support or interfere with the realization of the right to health during the Zika epidemic—can guide policymaking in different contexts.

Accountability as a Cross-Cutting Principle

Human rights identify duty bearers as responsible for respecting, protecting, and fulfilling interrelated rights. The application of human rights underscores the importance of having accountability mechanisms in place to ensure that appropriate actions are being taken to address public health emergencies—recognizing that policymakers and public health officials are responsible for long-term consequences of responses. In politically restive countries, government scandals and faltering health services may fuel conspiracy theories and larger-scale distrust of government, compromising the success of state-led public health efforts (D. Diniz and O. Cabrera, telebriefing to funders' network on civil society responses to Zika in Latin America, March 2016). In Brazil, for example, when media diverted attention from Zika to impeachment proceedings of then-President Dilma Rousseff, reduced pressure to hold the state to account for its response to Zika may have jeopardized the ability of affected families to receive necessary medical and social services. Accountability for action on Zika is also threatened in Puerto Rico, which is facing the biggest debt crisis in its history. The CDC estimates that more than 33 260 people have been infected with locally acquired Zika in Puerto Rico, with more than 2639 cases in pregnant women across US territories.[38]

After Ebola, the responses of international agencies to Zika are under scrutiny. The declaration by WHO of Zika as a Public Health Emergency of International Concern likely aided in harnessing global resources, but in the absence of data on the absolute risks of infection, it may have inadvertently licensed governments to misplace responsibility for the effects of Zika onto pregnant women. A constellation of accountability mechanisms including community surveys, "watchdog" civil society reporting, use of the courts, and national and international human rights monitoring tools can encourage governments to meet their Zika-related human rights obligations.

Unfortunately, no accountability mechanisms can ensure that countries act on their stated commitments, and compelling governments to act on inequities is a fundamental challenge. Some outbreaks may provide a unique, time-sensitive opportunity to act on inequities, as they highlight not only disparities but also weaknesses in social institutions, thereby potentially fueling social movements. By addressing structural and social determinants of health in a public health crisis,[30] a rights-based response would seek accountability for both the provision of community-responsive

information and services relevant to Zika as well as longitudinal projects on water, sanitation, education, and housing that are at the root of viral spread. Zika can therefore serve as a spur, nudging governments to advance human rights when those actions—though always needed—might otherwise not be taken.

It may seem challenging to prioritize responding to Zika when basic needs are not being met. However, the confluent biological, political, and social factors at play pose significant consequences for affected communities more generally. Appropriate action on Zika may therefore have broader population health benefits. Although decisions as to which actions to take are highly context-specific, a rights-based approach allows for progressive realization, responding to local realities in which concrete benchmarks and targets can be set and monitored.

CONCLUSIONS

Here, we have engaged human rights and related principles to identify shortcomings and describe ways in which 4 categories of public health responses to Zika can be made more equitable and, therefore, more effective and sustainable. In particular, the application of human rights suggests that ongoing responses need to prioritize the economically and geographically marginalized populations most vulnerable to infection; incorporate poverty reduction and action on the underlying determinants of health including water, sanitation, and housing; and explicitly consider strategies to make the legal and policy context as conducive as possible. Participation of affected families will be particularly important in appropriately organizing health systems to meet heightened demand for family planning, counseling, and antenatal testing as well as specialized care for children with congenital Zika syndrome. Interventions that neglect the human rights–based suggestions identified here—or fail to prioritize action on Zika altogether—may inadvertently exacerbate the health and social impacts of the epidemic.

When the initial alarm and focus on Zika fade, will our actions have met the needs and rights of the most affected populations? The consequences of this Zika outbreak will be enduring: children with congenital Zika syndrome require longitudinal care, and affected families will likely face an uphill battle for access to adequate health and social services. A human rights approach not only ensures that the dignity of affected families is respected, but also advances societies' collective ability to address future public health emergencies. Human rights are a critical but as yet inadequately addressed component of ongoing Zika responses. AJPH

CONTRIBUTORS

All of the authors contributed substantially to the conceptualization and analysis of ideas presented in this article and to the drafting and revising of the article, and they approve the final version.

ACKNOWLEDGMENTS

We are grateful to Kumanan Rasanathan for his insightful comments and suggestions at various stages in the preparation of this article. We also wish to acknowledge the input of Kiti Kajana Phillips and Elisa Slattery during initial conversations about Zika and human rights.

HUMAN PARTICIPANT PROTECTION

Human participants were not involved in developing the analysis expressed here, and institutional review board approval was not needed.

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