

Ethical Issues during Zika Epidemic in Puerto Rico and the Americas

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The Zika virus epidemic and the possible devastating teratogenic effects of the virus represent a challenge. Health authorities have the responsibility to create programs that provide adequate preventive, medical and psychological services to the affected population. The estimated risk of microcephaly in infants of mothers infected with Zika virus is 1 to 13% when the infection occurs in the first trimester of pregnancy. There is insufficient data to estimate the risk of microcephaly when infection occurs in the second or third trimester. Pregnant women and those in reproductive age are advised to avoid traveling to places where there is local transmission of the Zika virus. Human rights advocates have requested, comprehensive sexual and reproductive health services that include expanded access to contraceptive methods including emergency contraception and safe abortion services. These strategies created a debate between the abortion rights and the right of the disabled. The discussion rests on the assumption that there are lives that are not worth living. Most people focus on the most severely affected patients, but few consider that the spectrum of disabilities associated with congenital Zika infection is broad. The rights of children with disabilities and their dignity as individuals should be respected. [P R Health Sci J 2018;37(Special Issue):S41-S44]

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Devaluation of the most vulnerable, as infanticide, dates back to ancient Greek and Romans. Direct killing of the child was a common and direct method (1). A more vague and subtle method known as “exposure” or exposition was also used. Exposure were actions taken to get rid of “the burdens and liabilities of the infant and was not considered direct killing” (2). A modern version, in America, was unwillingness to intervene in children with congenital or perinatal conditions in which surgery would have been a life-saving procedure. Those children were considered lives not worth living, and surgery on them was considered futile (1). Modern diagnostic tools such as amniocentesis and ultrasound allow prenatal detection of “worthless” lives and their early termination, contrary to the biomedical ethics dictum of “avoid killing innocent humans” (2).

The Zika epidemic in many American countries and the teratogenic effect of the virus, particularly in the brain has reignited the abortions’ rights debate, and on the rights of the disabled (3). Misinformation, by a sensationalist media, ideologies foreign to the best interests of the child, and other factors were able to legitimize, crisis management strategies, not compatible with those proposed by health care authorities nor adequate medical practice. Before enough evidenced based public health strategies could be developed, birth control of exposed women of childbearing age and termination of at risk pregnancies were implemented. Disregarding the fact that the child by reason of his physical and mental immaturity

needs special safeguards and care, including appropriate legal protection, before as well as after birth.

Zika virus transmission in the Americas begins in Brazil in 2015. As of October 2015, 69 countries and territories have reported local transmission of the Zika virus. Puerto Rico reported the first case on December 31, 2015. At the moment there are 40,460 confirmed cases, of which 3,923 are pregnant women (4).

A pregnant woman can transmit the Zika virus to the fetus at any time during the gestational period. The virus has been demonstrated in fetal tissue, amniotic fluid, placenta, and brain tissue. In April 2016 the Centers for Disease Control and Prevention (CDC) concluded that the Zika virus could cause microcephaly and other serious brain defects (5,6). At this time we do not know the risk of microcephaly in infants of mothers infected with Zika virus, but based on data from the outbreak in Brazil the estimated risk is 1 to 13% when the infection occurs in the first trimester of pregnancy. There is insufficient data to estimate the risk of microcephaly when infection occurs in the

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second or third trimester. Some babies with congenital Zika virus infection who are not born with microcephaly may develop poor head growth and postnatal microcephaly. Decreases in the rate of head growth postnatally in these infants can be associated with significant neurologic dysfunction, including hypertonia and hemiparesis, dyskinesia, dysphagia, epilepsy, and persistence of primitive reflexes. Also, ventriculomegaly, decreased brain volume, cortical malformations, and subcortical calcifications have been reported in these infants (6).

The size of the head reflects the size of the brain, but the effect on the child's development cannot always be predicted. Although some children with microcephaly may have developmental disabilities, others do not have significant health problems. Infection with the Zika virus in the late stage of pregnancy, including the period immediately preceding the birth and the first few days after birth, has not been associated with cases of microcephaly. Not all babies whose mothers had Zika during pregnancy are born with health problems. The United States Pregnancy Registry and Zika reported that about 6% of women with recent Zika virus infection had babies with virus-related congenital defects. Some of these defects include eye defects, hearing loss, and developmental disorders.

At the beginning of the epidemic, it was believed that the virus could be transmitted only by the bite of the mosquito, but sexual transmission of the virus was demonstrated. A great deal of knowledge about Zika virus infection has been gained during the past few months, but many things are still uncertain. The risk of damage to the fetus as a result of perinatal infection and the spectrum of involvement of congenital Zika syndrome is unknown. The period during the maternal infection during which the fetus is at risk is unknown, and it is uncertain if a previous infection with Zika confers immunity for future pregnancies. At this time a rapid test for the detection of Zika virus is not available, and there is no treatment for pregnant women or a vaccine to prevent perinatal infection.

On February 1, 2016, the World Health Organization (WHO) declared a Public Health Emergency of International Concern, in response to reported cases of microcephaly and neurological disorders and their possible association with Zika virus infection. As a result of the increase in the number of babies born with microcephaly in poor communities in Brazil, an investigation was conducted to determine the possible association with viral infections. In April 2016 it was concluded that maternal infection with the Zika virus during pregnancy caused spontaneous abortions and neurological malformations including microcephaly, but also motor, ocular and auditory problems. Women in 29 countries have had babies affected by congenital Zika infection. In Puerto Rico, a total of 47 infants with malformations associated with intrauterine infection with Zika virus have been reported. These include abnormalities of the brain with or without microcephaly, neural tube defects and other malformations of the brain and the eyes.

The impact of the Zika epidemic on the physical and emotional health of the vulnerable population is high. In

the absence of immunity against infection, countries have designed multiple strategies to stop the spread of the virus and prevent the devastating effects on the health of newborns. The first strategy was to control the vector to reduce fetal exposure to the virus. The Centers for Disease Control (CDC) recommended pregnant women and those in reproductive age to avoid traveling to places where there is local transmission of the Zika virus.

Other strategies were directed at the sexual and reproductive health of the population. Once the sexual transmission of the virus was confirmed, the CDC recommended women to avoid unprotected sex with men who live or have visited areas endemic to Zika. Some countries even recommended that women avoid pregnancy for two years. Some human rights advocates have requested comprehensive sexual and reproductive health services that include expanded access to contraceptive methods including emergency contraception and safe abortion services. The World Health Organization (WHO) believes that women who want to terminate their pregnancy for fear of microcephaly should "have access to safe abortion services according to the law". In some countries like Brazil, where abortion is illegal, many women, faced with uncertainty, have opted for clandestine abortions placing their health at risk. Women who develop complications do not seek medical care due to the fear of criminalization and imprisonment.

In Puerto Rico, birth control clinics were established with a network of providers that provide contraceptives to the entire population without charge. These efforts have resulted in a significant decline in the birth rate of the country.

Another aspect of paramount importance is the response of health systems, which includes preparation and reorganization to meet the care needs of children born with congenital Zika. These include medical services, physical and occupational therapy among others. Some of these services are expensive and are not covered by health insurances. The Puerto Rico Health Department established guidelines for the evaluation and diagnosis of infants with possible congenital infection with the Zika virus. These guidelines establish laboratory and diagnostic tests that should be performed on all newborns with and without evidence of abnormalities at birth. In addition, it provides the long-term follow-up of infants born to mothers with Zika virus infection. This program guarantees access to the multidisciplinary services required by the patients and their families.

The Zika epidemic has again aroused the discussion of the right to abortion and the rights of the disabled. People in favor of abortion, have advocated this alternative for pregnant women with Zika due to the risk of having a disabled child. This option is presented to women living in populations of scarce resources, where abortion is restricted, influencing these vulnerable populations. One of the groups which have placed pressure on governments to make abortion available to all women, is "Women on the Web". They provide guidance and access to birth control and abortion pills to women who request them.

They argue that the right to abortion should be a private matter of women and not a political issue (7).

On the other hand, the people with disabilities advocate for the right to existence. Arina Grossu, Director of the Center for Human Dignity at the Family Research Council, claims that killing people with special needs contradicts the fundamental need of society to protect the most vulnerable (8).

The Zika epidemic has highlighted the way that people around the world continue to discriminate against people with disabilities. The discussion of microcephaly in infants of mothers with Zika rests on the assumption that there are lives that are not worth living. The press focuses on the most severely affected, but few considered that people with disabilities could lead a life full of affection.

Rosemarie Garland-Thomson, scholar studios of disability, makes us consider that we must be aware of the stories of discrimination that have modulated our perception of the disabled, and work to expand both resources and our thinking, so that persons with disabilities have the opportunity to live good lives (9).

The Zika virus is neurotropic, but the degree of harm to the fetus depends on the moment in the development of the fetus in which the woman is infected. Policies for the prevention of Zika in women of childbearing age were focused on birth control and interruption of pregnancies. JAMA reported that 6% of infants of mothers with Zika had birth defects (10). With the difficulty to determine quickly who the women at risk were; recommendations which violated the autonomy of pregnant women resulted in many women desperately looking for solutions which were poorly informed, and lead to make unfortunate decisions.

The American College of Obstetrics and Gynecology determined that obstetric care providers should counsel pregnant women, exposed or infected with the Zika virus, regarding their options, including termination of pregnancy. This recommendation was stated despite the fact that at that time the evidence of the effects of the Zika virus in the fetus was lacking and that they recognized that there was much uncertainty as to which fetuses were affected. They acknowledged that the woman, who decided to have an abortion, should be helped to achieve it, though it might be necessary to send them to other states where second trimester abortions could be done (11). Little is known of the rate of transmission of the virus from mother to the fetus and the risk of congenital anomalies in the fetus (12,13). Laboratory tests to confirm infection by Zika have many limitations. Even in places where the diagnostic tests are done the results are not readily available. Serologic tests for the presence of infection may give false positive and false negative results making it difficult to exclude infection. The CDC has reported only 25% of the possible infants infected by Zika in the United States have had head ultrasounds done.

The Zika epidemic and its possible devastating consequences on children's health is a challenge to our communities. The Zika epidemic affected predominantly poor vulnerable populations

where there was lack of adequate medical services and the infrastructure to help children with disabilities. The access to health services, particularly services to the infected children, should have been the priority. The lack of specialized medical and psychological services further compromised the well being of these populations. The legacy of the epidemic will last years and the struggle of the affected children to have access to the services they need and are entitled to, is only beginning. It is important to make sure that not only their rights, but their dignity as individuals are respected.

Resumen

La epidemia del virus Zika y los posibles efectos teratogénicos devastadores del virus representan un desafío. Las autoridades sanitarias tienen la responsabilidad de crear programas que proporcionen servicios preventivos, médicos y psicológicos adecuados a la población afectada. El riesgo estimado de microcefalia en lactantes de madres infectadas con el virus Zika es del 1 al 13% cuando la infección ocurre en el primer trimestre del embarazo. No hay datos suficientes para estimar el riesgo de microcefalia cuando la infección ocurre en el segundo o tercer trimestre. Se aconseja a las mujeres embarazadas y a las mujeres en edad reproductiva que eviten viajar a lugares donde haya transmisión local del virus de Zika. Los defensores de los derechos humanos han solicitado servicios integrales de salud sexual y reproductiva que incluyan un mayor acceso a los métodos anticonceptivos, incluyendo la anticoncepción de emergencia y los servicios de aborto seguro. Estas estrategias crearon un debate entre el derecho al aborto y los derechos de los discapacitados. La discusión se fundamenta en el supuesto de que hay vidas que no valen la pena vivir. La mayoría de las personas se centran en los pacientes más gravemente afectados, pero pocos consideran que el espectro de discapacidades asociadas con la infección congénita de Zika es amplio. Los derechos de los niños con discapacidades y su dignidad como individuos deben respetarse.

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