

## ARTIGO ORIGINAL

# "I don't know if I have the courage": reproductive choices in times of Zika

Ana Rosa Linde Arias<sup>1</sup>, Elisa Tristan-Cheever<sup>2</sup>,  
Grace Furtado<sup>1</sup>, Eduardo Siqueira<sup>3</sup>

<sup>1</sup>The Mauricio Gastón Institute for Community Development and Public Policy, University of Massachusetts-Boston, USA

<sup>2</sup>Cambridge Health Alliance, Cambridge, MA

<sup>3</sup>The School for the Environment, University of Massachusetts Boston, USA

autor correspondente: anarosa.lindearias@umb.edu

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## Resumo

Neste estudo transnacional, pretendemos fornecer informações sobre as opiniões e atitudes das mulheres em relação aos seus direitos reprodutivos durante a epidemia do Zika. Mulheres de diferentes nacionalidades e etnias foram recrutadas em vários locais do Brasil, Porto Rico e Estados Unidos. Foram realizadas entrevistas semiestruturadas que sugerem que as decisões reprodutivas dos participantes estavam intimamente relacionadas às convicções pessoais e crenças culturais, e suas ações e pensamentos foram incorporados em suas normas socioculturais. A maioria das mulheres entrevistadas comunicou que é preciso coragem para tomar a decisão extrema, emocional e esmagadora de fazer um aborto. Os achados deste estudo sugerem que mulheres de diferentes países e regiões, e com diferentes níveis de capital social, enfrentam os mesmos conflitos relativos às decisões reprodutivas. Assim, defendemos a importância de considerar crenças e comportamentos culturais ao implementar medidas de prevenção ou proteção à saúde para controlar epidemias. Esta epidemia pode ser mais uma oportunidade para melhorar a saúde das mulheres, fortalecendo serviços de planejamento familiar culturalmente sensíveis e um amplo espectro de intervenções de saúde pública.

**Palavras-chave:** mulheres, Zika, direitos reprodutivos, aborto, escolhas reprodutivas.

### Por que este estudo foi feito?

We aimed at providing insights into women's views and attitudes towards their reproductive rights, and at exposing the psychosocial and cultural factors affecting women during the times of Zika. We focused on the reproductive choices of women indirectly affected by the disease, because to our knowledge the literature on the Zika epidemic concentrates on the impact of the disease on women who delivered babies with microcephaly.

### O que os pesquisadores fizeram e encontraram?

We interviewed women from various locations in Brazil, Puerto Rico, and the United States and of distinct nationalities and ethnicities. They indicated that their reproductive decisions were intimately related to personal convictions and cultural beliefs, and their actions and thoughts were embedded in their sociocultural norms. The majority of women interviewed communicated that it takes courage to make the decision to have an abortion.

### O que essas descobertas significam?

The findings of this study suggest that women from different countries and regions, and with different levels of social capital, faced the same conflicts concerning reproductive decisions. Thus, we argue for the importance of considering cultural beliefs and behaviors when implementing health prevention or protection measures to control epidemics.

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## ■ INTRODUÇÃO

In May 2015, the Pan American Health Organization (PAHO) issued an alert regarding the first confirmed Zika virus infection in Brazil. Subsequently, on Feb 1, 2016, the World Health Organization (WHO) declared that the Zika virus was a public health emergency of great international concern<sup>1</sup>. In November 2016 the WHO downgraded Zika from a public health emergency to a "common threat," while more than 70 countries and U.S. territories continued to report active Zika virus transmissions<sup>2,3</sup>. The Zika virus can cause congenital brain abnormalities during pregnancy<sup>4,5</sup> which led governments, national and international agencies to issue advice and recommendations to safeguard women from infection<sup>6</sup>. For example, a number of governments in Central and South America recommended that women avoid pregnancy or delay it through 2018<sup>6</sup>. The CDC recommended couples with a male partner traveling to an area with the risk of Zika infection to consider abstinence or the use of condoms for at least 6 months. In the case of a female partner traveling to those areas, even without symptoms, the CDC recommended family planning via the use of sexual abstinence or condoms for at least 8 weeks.

At the height of the epidemic, the United Nations High Commissioner asked Latin American countries affected by Zika to allow women to access birth control and abortion. Even Pope Francis recognized the infection's consequences, stating that "avoiding pregnancy is not an absolute evil"<sup>7</sup>, thus demonstrating that contraception methods could be offered to Catholic women. Yet, not everyone has the same access to reliable forms of contraception and in numerous countries of the region abortion is illegal. In Brazil, the country most affected by the Zika outbreak, abortion is illegal, as in several other Latin American countries, including Colombia, El Salvador, Venezuela and Peru.

Despite the widespread opposition to legalizing abortion, many Brazilian physicians supported abortion access for women infected by the virus citing the precedent of preventing fetal anencephaly as a reason for legal abortion. Furthermore, the presiding Colombian Health Minister, Alejandro Gaviria Uribe, backed the idea that women should be allowed access to terminate a pregnancy. However, to date the changes in legislation in either country have yet to take shape<sup>8</sup>.

On the other hand, abortion has been a legal procedure in the United States since the landmark Supreme Court decision, *Roe v. Wade* in 1973. Recent years have seen an uptick in restrictions on obtaining the legally sanctioned procedure throughout various corners of the country. During the spring of 2017, legislators in six states introduced bills banning all abortions, while in 28 states bills were submitted to allow abortions only under special circumstances, such as during the early stages of pregnancy<sup>9</sup>. Due to the Commonwealth standing of Puerto Rico, a territory vastly affected by Zika, the *Roe v. Wade* decision regarding the legality of abortion is upheld; however, there is a "criminal abortion statute in the books that prohibits performing or undergoing an abortion for reasons other than protecting the woman's

life or health"<sup>10</sup>. During the Zika outbreak the Puerto Rican government implemented the Contraception Access Network (Z-CAN), a short-term response from May 2016, to September 2017, for rapid implementation of reversible contraceptive services to control the mosquito borne virus<sup>11,12</sup>.

As a result of the Zika epidemic, women's reproductive health has been thrust into the limelight<sup>13,14</sup>, but this issue is not new for women. The topic of women's health has a long and loaded history due to its link with deep seated religious and moral beliefs, legal traditions, and a strong emotional bias that almost blocks any rational approach to the pro-life versus pro-choice debate<sup>15</sup>. In the mid-20th century, rubella or German measles, another contagious, viral infection that can lead to birth defects during early pregnancy, such as cataracts, deaf-mutism, heart disease, microcephaly and mental retardation, stirred up strong debate about access to safe and legal abortion procedures<sup>16</sup>. The United States experienced an outbreak of rubella in 1964 and 1965, and public health officials warned women about the potential adverse effects on unborn fetuses. Regardless of the illegality of abortion at the time, criminal law allowed physicians to perform "therapeutic abortions" for medically sanctioned reasons. The rubella outbreak laid the groundwork for a social movement that resulted in the legalization of abortion in the early 1970s<sup>17,18</sup>.

Approaches to understanding and resolving reproductive issues continue to frame women's bodies as the source and focus of ethical decisions and diseases. For example, the international debate about the Human Papillomavirus (HPV) initially concentrated on only vaccinating women though the virus is transmitted via sexual contact from men to women, men to men, or women to men. This biased view affected women's health practices and policies related to the sexual and reproductive responsibilities of women<sup>17</sup>. An overdue burden is placed on women in the realm of sexual reproduction to prevent the spread of sexually transmitted infections and the possibility of impregnation. On the other hand, women's health professionals recognize that governments and other non-governmental agencies should not impose reproductive choices on women<sup>18</sup>, especially when sociocultural factors are not taken into consideration, including socioeconomic inequality, socioeconomic position, the emotional burden on women, and gender differences in reproductive decision-making.

The evidence that the Zika epidemic is a public health concern in need of urgent remedy is not controversial, and there is consensus about finding and implementing effective solutions to the Zika virus infection. However, while there is no dispute regarding the existence of racial and ethnic disparities in women's health, there is a clear need to consider women's choice in reproductive decisions, and to develop and improve reproductive health policies<sup>19,20</sup>.

Few peer-reviewed studies address the views, attitudes and beliefs on reproductive decision-making and reproductive rights of women affected by the Zika

epidemic. In this transnational pilot study, we aimed at providing insights into women's views and attitudes towards their reproductive rights, and at exposing the psychosocial and cultural factors affecting women during the times of Zika. Our study focused on the reproductive choices of women indirectly affected by the disease, because to our knowledge the literature on the Zika epidemic concentrates on the biomedical impact of the disease on women who delivered babies with microcephaly. We also sought to identify the long-term repercussions of the epidemic in women's lives to support public health policies that respect the feelings and beliefs of all women, not only of those who were mothers, pregnant, or intended to become pregnant.

**MÉTODO**

We conducted semi-structured interviews of 24 women who lived in various locations in Brazil, Puerto Rico, and the United States, and self-identified as Brazilian, Hispanic or Whites. They were from diverse nationalities, socioeconomic positions, religions, and cultural backgrounds. They resided in two countries and a U.S. territory that have different legal systems, public health policies, and socio-cultural contexts. We chose Brazil and the U.S. as sites for the study because all authors lived in Massachusetts but some had strong professional and personal connections in Brazil. Participants were recruited by personal contacts of investigators and community associations following the snowball sampling technique. We recruited women of reproductive age (18-45 years old) who lived in or migrated from countries or U.S states where the Zika virus was detected.

The interview guide was pilot-tested with a couple of interviewees to test for reliability and validity. Revisions were made according to the feedback provided. It included topics such as women's personal and family life, perceptions and knowledge of Zika, views on reproductive health and rights related to the Zika syndrome. Additional in-depth interviews with six key female informants, who worked directly with women affected by the Zika virus, were also conducted to collect expert information on the impacts on such women. These key informants included: a female official of the Brazilian Minister of Health of Brazil in charge of providing assistance to mothers of children with microcephaly; a female psychologist who provided care to mothers in Rio de Janeiro, Brazil; a female pediatrician in Boston who worked with Latino Communities, a female researcher in Puerto Rico who worked in Public Health, a female doctor in Florida who worked with pregnant women, and a female researcher at Yale who worked with women and reproductive rights in North and South America.

Interviews were conducted by the first author between October 2016 and June 2017 in English, Brazilian Portuguese, and Spanish. Eight interviews were conducted in person while 16 interviews were conducted via Skype. The average length of interviews was 2 hours. The interviews were transcribed verbatim in English, Portuguese, or Spanish by research assistants who were native speakers of each language. The audiotaped and transcribed interviews were kept anonymous and all

transcriptions were double-checked for accuracy by Dr. Linde, who coded them for themes using NVivo software® for qualitative data analysis. With the input of Dr. Siqueira, Research Assistant Grace Furtado and Dr. Tristan-Cheever, Dr. Linde created the code tree to organize frequent themes. The content of the code tree was discussed in detail during several meetings before consensus was achieved. Pseudonyms were adopted for all participants to maintain anonymity.

The research protocol was approved by the Ethics Committee of the Institutional Review Board of the University of Massachusetts Boston under number 2016186. All participants were informed of the study aim and procedure and advised that participation was voluntary and confidential. Written consent was obtained from those who agreed to participate in the study.

**RESULTADOS**

**Participant Characteristics**

Table 1 displays the sociodemographic characteristics of participants. The ages of the women varied between 22 and 41 years old. Nine women had long-term partners while 15 were married. The women resided in Florida, Massachusetts, Washington D.C., Puerto Rico and several localities in Brazil. Brazilian, Hispanic and White races/ethnicities were represented.

**Table 1:** Sociodemographic Characteristics of the Women Interviewed

Characteristic	n
Age	
22- 30	9
31-41	15
Ethnicity	
Brazilian	11
Hispanic	9
American	4
Civil Status:	
Married	15
Long term Relationship	9
Maternity status	
Recently born baby	6
Pregnant	8
Planning to get pregnant	6
No plan to get pregnant	4
Residence	
Brazil	9
Washington DC	1
Massachusetts	4
Florida	5
Puerto Rico	5

Twelve participants had been pregnant recently or were pregnant at the time of the interview, while six were planning to become pregnant and six did not want to become pregnant but lived in locations affected by the

Zika virus. Two participants were misdiagnosed with Zika infection while pregnant, 1 had a husband diagnosed with the virus while pregnant, 1 was suspected of bearing a child with microcephaly, and 5 had a positive diagnosis of Zika though not pregnant. All participants had at least high school education. Five held PhD degrees, 3 Master's degrees, 3 postgraduate studies, and 7 had college degrees. Participant religious beliefs were the following: 12 Catholic, 5 Evangelist, 5 Spiritist, 1 Agnostic, and 1 Atheist.

### Thematic Analysis

Most participants understood the choice for an abortion by other women resulting from socioeconomic and health reasons, but when asked whether they personally would choose an abortion, responses were almost unanimously negative. The need to respect life based on their personal beliefs regarding abortion was very clear in their answers. A few women viewed abortion as a crime, ungodly even, regardless of the real likelihood that they could give birth to a baby with abnormalities and possibly a future life without normal development. Giselle, for example, stated: "I understand that the person has the right to choose. However, if you are asking what I think, my religion declares that the woman should have [the baby]" (41 years, pregnant).

Some participants seemed to not only associate spiritual beliefs with the right for abortion, but also felt emotional ties with the fetuses they carried:

*"I believe that it depends of the degree of malformation if I would accept it. Because to carry a full-term pregnancy and to know that in the end the baby is going to die, I believe that it is a sadness, a suffering for the mother, because you have a relationship with the baby that is growing inside your belly.... Yes, last resource."*

(Denise, 33, pregnant).

All participants were aware of the potentially illegal status of abortion in their respective countries, although they expressed distinct viewpoints regarding abortion. For example, Kenia, a Puerto Rican who resided in Puerto Rico, believed that abortion was not legal on the island, though it is. A potential interpretation for this misconception is the unconscious rejection of the procedure due to her moral beliefs. She defined herself as "Cristiana" or Christian:

*"No, it is illegal! In Puerto Rico, we don't support the abortion. It is supposed that this [abortion] is not done here in Puerto Rico. The staff [providers] do not insist to have the interruption of the pregnancy. Only in the extreme case, really extreme. That the baby comes for example with something like a cerebral problem or is dead. Things like that, but specific because of this [Zika], no."*

(27, pregnant)

Each participant from countries where abortion is illegal had a unique way of expressing their opinion about legal alternatives. Some, as Fanny, revealed their activist and more realistic view, pointing out differences that occur

due to the socioeconomic status of women:

*"There are many abortion clinics, right? Everyone who has a little more money can abort. Only poor Brazil does not abort. I think. I am in favor of legalizing abortion in general, so that's a difficult question for me. So, for me, I do not think it should be legal just because of it. I think abortion should be legal in Brazil... Not necessarily because of microcephaly, but because I think it's a public health problem, I think the woman has the right to choose"*

(Fanny, 37, not pregnant).

Renata, agreeing with Fanny, explained the necessity to legalize abortion to decrease the number of deaths due to clandestine procedures:

*"Well, I am in favor of the legalization because we have many people dying in Brazil because they do it, do with risk to health. Because when I was pregnant, this was the concern, if the child is ok, if it has any disease, something worse. However, with Zika, if you know, if you have an exam. Well, I don't know if we have an exam that checks for microcephaly early on ...but I am in favor [of the legalization of the abortion]"*

(Renata, 41, not pregnant).

Although a few women claimed to respect the choice of others to have an abortion as a means to confront malformations or other concerns resulting from contracting Zika, many women indicated subtly that they judged negatively such a decision. As one interviewee expressed, when referencing the choices made by another woman:

*"...she had an abortion because she got involved with someone who did not want and was not going to support [the child], the repeating story that does not justify an abortion, but in the end, that is her option. They risk their lives not to have a baby. I go through all of this, so many people don't want to have a baby, and I wanted to have a baby..."*

(Denise, 33, pregnant)

Some participants also suggested that in case of enactment of an abortion law, Brazilian women were not prepared to have the procedure. When discussing more vulnerable populations, such as women from lower socioeconomic position or adolescents, one of the participants stereotyped teenage women as irresponsible who could take advantage of the new law and use it as an excuse for their faulty behavior. The reasons offered for their opinions on abortion gravitated around the ignorance on the topic and the Zika virus by the population, and a presumption that abortion prohibition suppresses the free life style of young adult women:

*"Because. It can be a gateway to many different problems. Many young girls will get pregnant at a very, very young age. With lack of knowledge, proper monitoring and structure, these thirteen, fourteen-year-old girls are not in any condition to have children and then they go and abort them. As*



*an easy solution for them. I see it as a trivializing concept. Comparing it to a headache, for example. "Oh I have a headache, take some medication and the headache goes away". You know what I mean? It becomes something so simple when in reality I think this is very serious. Whether you like it or not, you are dealing with someone's life. I just don't believe that is the solution"*  
(Marisa, 35, pregnant).

There were a number of women on the frontlines of the Zika epidemic, who had shifting views on abortion, and its relation to their personal lives. Despite the fact that most women interviewed were in favor of access to legal abortions, only a few admitted that they would in fact have a procedure without reservations.

## ■ DISCUSSÃO

The majority of women interviewed communicated that it takes courage to make the extreme, emotional, and overwhelming decision to have an abortion. Despite the fact that most participants were from higher socioeconomic status (here assessed as occupation and education level), their reproductive decisions were closely connected to personal convictions and cultural beliefs. The findings of this study suggest that women from different countries and regions, and with different levels of social capital, faced the same conflicts concerning reproductive decisions. Participants described actions and thoughts that reflected deeply embedded Latino (and Brazilian) sociocultural norms. The fatalistic "acceptance of one's fate" without question or personal control. It was demonstrated through participants' words and spiritual beliefs, the Latino cultural fatalism. According to this worldview, the course of fate cannot be changed, and life's events are beyond one's control<sup>21</sup>. Evidence of this thought process is apparent when the women claimed non-negotiable dedication to support an unhealthy child in order to fit the norms of their belief systems. In this view, control is in the hands of God, the Almighty.

The popular saying "Yo creo que pasa lo que Dios quiere" [I believe that things happen as God wants] reflects Latino women's acceptance of pregnancy as God's wish. Thus, they must accept their destiny and take care of a child with microcephaly. Contrary to media portrayals of Zika and microcephaly as tragic disabilities, mothers that have children with such malformations do not necessarily lament their condition. Actually, many consider their children a blessing from God and have rallied against the socioeconomic inequities in Brazil that fueled the epidemic and worsened in its wake<sup>22</sup>.

Most women interviewed would not choose abortion as a viable option. Latino theological literature and health care studies of Latinos discuss the importance of this culture's everyday faith experience to obtaining medical care<sup>23</sup>. Faith and spirituality are part of the worldview of almost all participants, even when they tried to hide their profound and entrenched moral and religious beliefs. Therefore, it is essential to consider the many years of moral and religious doctrines that shaped family and social norms of Latino and Brazilian women. For

several participants, abortion was against their beliefs, and viewpoints about their reproductive lives were confined to the expectations of the Religious communities. The negative view of Brazilian interviewees towards abortion indicate that this procedure is a topic of contention heavily influenced by cultural, religious and sociological factors.

As previously mentioned, Brazil was the country most affected by the epidemic, though women are not protected by legal abortions regulations<sup>24-26</sup>. The need for a resolution concerning the legalization of abortion in Brazil was reported by many Brazilian interviewees. Although a number of women believed that an abortion law should be approved to give choice to women, they argued that conflicts could arise, especially for young women who were viewed as not mature or sufficiently informed to make such an important decision. This argument is part of the same overall debate, where women are stigmatized and stereotyped not just for becoming pregnant or having a child with a disability<sup>27</sup>, but also for their ignorance about contraceptive methods or living a libertine lifestyle.

The difficult advancement of reproductive rights in Brazil, as well as in other countries, is an arena of dispute and tensions<sup>28,29</sup>, where problems of access to information and inputs related to reproductive planning exist, and where setbacks in the field of reproductive rights are possible<sup>21,22,30</sup>. Publications of researchers and feminists, especially Brazilian women, about reproductive autonomy, reproductive planning and legalization of abortion in the context of Zika, point out women's constraints in exercising autonomy over their bodies, lives and reproductive choices<sup>31-33</sup>. However, other studies claim that the focus on abortion legalization by some as a response to the Zika virus is misplaced<sup>21,29,34</sup>. We argue that it was not a good idea to have this debate during Zika outbreak, because the moral controversies of abortion distracted policymakers from what needed to be done to address the outbreak.

Government backing during the Zika outbreak existed for women through support groups, programs and campaigns. Nevertheless, it is not clear that this support was the most appropriate or effective. As part of the discussion regarding government policies to address the Zika epidemic, it is important to take into consideration – and the evidence is convincing- that the poor are more likely to contract Zika<sup>35-37</sup>. Low socioeconomic position families face the worst challenges in raising a disabled child, or choosing an abortion.

Our study suggests that a fair approach to the issue would ensure that women have the right to make an informed choice about whether to terminate a pregnancy without external pressure or constraints. When deciding to go on with a pregnancy, the state should provide them and their family with the resources and support to do so.

Although the incidence of Zika cases has declined, the threat still remains. A new epidemic of Zika is possible, and could be exacerbated by climatic conditions<sup>38,39</sup>. On the other hand, the health and social consequences of the 2015–2016 epidemic should encourage strategies that properly address women's reproductive health and rights. The Zika virus outbreak is an opportunity to improve

women's health by strengthening culturally sensitive family planning services.

Through one-on-one interviews we developed a more in-depth understanding of the impacts Zika has on women's lives. Our analysis of the impacts of Zika on a small sample of women provides input for future survey studies to measure those impacts in larger representative samples. But additional studies ensuring that the psychological, social and emotional factors of encountering Zika are needed. The Zika epidemic highlights the fact that on a worldwide scale women's health continues to encounter barriers for secure access to abortion. The women in this study were of distinct nationalities and ethnicities, and most had good education levels; yet, their actions and thoughts were embedded in their sociocultural norms. Our study shows the importance of considering cultural aspects and behaviors when implementing health prevention or protection measures to control epidemics.

Our study had limitations, such as the small convenient sample, which may be biased for not including a more racially and ethnically diverse representation of

women (African-American and Asian women in the U.S and Brazil were not included, for example). We may not have comprehensively analyzed the effects of Zika on women's health due to our expertise in other areas of public health and biological sciences. Further research may compare the experiences of women infected and non-infected with the Zika virus, but who could still feel anxious, neglected and isolated.

The dramatic impacts of the Zika epidemic are important to women's rights struggles in countries where abortion is illegal or even legal. This epidemic may be yet another opportunity for the improvement of women's health by strengthening culturally sensitive family planning services, as the unique costs of the mosquito-borne virus for maternal and perinatal health call for a broad spectrum of public health interventions.

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## Abstract

In this transnational study, we aimed at providing insights into women's views and attitudes towards their reproductive rights during the Zika epidemic. Women of distinct nationalities and ethnicities were recruited from various locations in Brazil, Puerto Rico, and the United States. We conducted semi-structured interviews that suggest that participants reproductive decisions were intimately related to personal convictions and cultural beliefs, and their actions and thoughts were embedded in their sociocultural norms. The majority of women interviewed communicated that it takes courage to make the extreme, emotional, and overwhelming decision to have an abortion. The findings of this study suggest that women from different countries and regions, and with different levels of social capital, faced the same conflicts concerning reproductive decisions. Thus, we argue for the importance of considering cultural beliefs and behaviors when implementing health prevention or protection measures to control epidemics. This epidemic may be yet another opportunity for the improvement of women's health by strengthening culturally sensitive family planning services, and a broad spectrum of public health interventions.

**Keywords:** women, Zika, reproductive rights, abortion, reproductive choices.

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