

# “Too Much to Ask, Too Much to Handle”: Women’s Coping in Times of Zika

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## Research article

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# Abstract

## Background and Objectives

Zika virus infection during pregnancy is a cause of congenital brain abnormalities. Its consequences to pregnancies have made governments, national and international agencies issue advice and recommendations to women. This study was designed to develop an initial understanding of the impacts of Zika on women of reproductive age who lived in areas with or without local transmission. The impacts on women who were less directly affected and less vulnerable to Zika were analyzed. The hypothesis was that all women were impacted by the epidemic.

## Methods

A qualitative study was carried out. Women were recruited through the snowball sampling technique from various locations in Brazil, Puerto Rico, and the United States. They were of different nationalities and ethnicities. Data were collected through semi-structured interviews. The data transcripts were analyzed using thematic analysis.

## Results

The social effects of the epidemic affect more women than had been thought before and at deeper emotional levels. Women perceived that the public health systems were placing an unfair responsibility for preventing health complications from Zika onto women who have limited ability. They also stated that the measures recommended to them were invasive, while creating the perception that women were the sole determinant of whether they contracted Zika. The results indicate that women with higher levels of education understood the limitations of the information, government actions, and medical care they received, which ended up producing higher levels of anguish and worry.

## Conclusions

Women appeared to be disproportionately affected by the reproductive implications of the epidemic, even when they were only indirectly affected. Gender inequality and gender discrimination must be recognized and rendered visible in the public health emergency response. It is shown the importance of considering cultural aspects and behaviors when implementing health prevention or protection measures to control epidemics.

# Introduction

In May 2015, the Pan American Health Organization issued an alert reporting the first confirmed Zika virus infection in Brazil. Subsequently, on February 1, 2016, the World Health Organization (WHO) declared that a massive Zika virus outbreak in the Americas was a Public Health Emergency of International Concern [1]. Today, while news media outlets are no longer concerned with Zika, and WHO recently downgraded the virus from a public health emergency to a “common threat,” more than 70

countries and U.S. territories continue to report active transmissions of Zika [2]. Without a doubt, concern should be raised not only regarding the likelihood of the virus persisting endlessly in current areas, but also about the danger of its spreading to new areas throughout the globe.

Generally, the Zika virus causes only a mild infection in humans, but for women who are pregnant it can produce severe neurological complications and adverse fetal outcomes [3]. During pregnancy, the Zika virus infection can trigger congenital brain abnormalities [4]. Moreover, sexual transmission of Zika from both male and female partners can occur [5,6] and the virus can remain viable in semen for months [7]. The risk of birth defects resulting from Zika infection during early pregnancy makes the virus an especially significant health threat for pregnant women and, more generally, women of childbearing age.

These unique consequences of Zika for maternal and perinatal health call for the implementation of a broad spectrum of public health interventions. Governments, along with national and international agencies, have issued general advice and recommendations to safeguard women from infection [8]. More specifically, many countries officially advised women to avoid becoming pregnant in Zika-affected areas [9], whereas others stressed the importance of obtaining counseling and sufficient access to family planning resources [10].

Preventive measures also include recommendations such as avoiding locations likely to contain infected mosquitos, covering oneself completely with clothing, and applying repellants, among other measures [11, 12]. Overall, there has been great concern with the biomedical aspects of disease transmission with regard to how transmission can be prevented through new vaccines or detection methods, and how to combat the proliferation or vector of the virus. The public health response to the Zika outbreak has mostly focused on epidemiological surveillance and vector control.

Few studies have so far been conducted to address the threatening effects that the Zika epidemic has on women's lives at a transnational level. Likewise, the ways in which women are psychologically and emotionally dealing with the threat of Zika outbreaks have yet to be documented. The psychosocial implications of the Zika epidemic are essential for a complete understanding of its long-term repercussions. To our knowledge, few studies discuss the impacts on women who are less directly affected and less vulnerable to Zika.

This study was designed to develop an initial understanding of the impacts of Zika on women of reproductive age who lived in areas with or without local transmission. Next, we describe and discuss the impacts of the Zika epidemic on women who either lived in areas where Zika infection was present, or were indirectly affected by the epidemic. Our hypothesis is that all women were impacted by the epidemic in some fashion.

## **Methodology**

This study adopted a qualitative research approach. Qualitative inquiry is used to explore and describe a poorly understood phenomenon that happens within a given context [13].

## 2.1 Data Collection

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 White. They had different nationalities, socioeconomic positions, religions, ages, 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 live in Massachusetts but have professional and personal connections in Brazil, the continental U.S., and Puerto Rico.

Participants were recruited by personal contacts of the investigators and community associations following the snowball sampling technique. Therefore, several of the interviewees trusted the interviewer and felt comfortable in providing sensitive information about their personal lives. We recruited women of reproductive age (18–45 years old) living or migrating from countries (such as Brazil, Venezuela, or Colombia) 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. 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. It was revised according to the feedback provided and allowed for participants to suggest new topics of interest.

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 first, second and third authors also transcribed the interviews. Dr. Linde's native language is Spanish, but she is also fluent in Brazilian Portuguese and English. Dr. Tristan-Cheever's native languages are Spanish and Brazilian Portuguese, but she is also fluent in English. Ms. Furtado is Puerto Rican and fluent in English and Spanish. The audiotaped and transcribed interviews were kept anonymous. Dr. Linde double-checked all recording for accuracy.

## 2.2 Data Analysis

The data transcripts were analyzed using thematic analysis, informed by a phenomenological perspective [14] in order to identify and analyze patterns and themes in the qualitative data [18]. The thematic analysis was approached as a 'bottom-up' process in which all data within the transcripts were examined and analyzed for patterns of meaning to explore what themes are important in addressing the research questions. Transcripts were systematically coded by Dr. Linde using NVivo software® for data analysis. An inductive analysis was performed rather than trying to fit the codes into a pre-existing coding frame [15]. The process began by generating a few free nodes; then ideas or key words derived from the interviews were used to code the text into themes. Dr. Linde collaborated with Dr. Siqueira and Tristan-Cheever to create the structure of the node tree. Dr. Siqueira and Dr. Tristan-Cheever coded several interviews independently and discussed the node tree with Dr. Linde in several meetings before consensus was achieved. We adopted pseudonyms for all participants to maintain anonymity.

## Results

### 3.1 Participant Characteristics

Table 1 displays the sociodemographic characteristics of participants. The ages of the women varied between 22 and 41 years of age. 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. 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.

### 3.2 Thematic Analysis

Our analysis identified several overarching themes related to Zika impact on women's family and personal lives.

#### *3.2.1 Biased Pressures on Women: "It is too much to ask, too much to handle"*

Many participants reported that there were social pressures on them to make sure that they did not contract the Zika virus. Many women felt that the government recommended measures inadequate for truly avoiding infection, while the accountability for avoiding the infection was placed solely on them. The recommended measures focused on changing daily habits, such as avoiding geographic locations likely to have intense infestations of the Aedes mosquitoes, covering oneself completely with clothing, and applying repellents that were persistent enough to stay on the body for extended periods. The

pressure to avoid contagion led many women, facing the potential to be infected with Zika, to feel guilty and lonely. As Ana C. summed up:

*"I felt I had failed at doing what I had especially and necessarily to do... and it's like... okay you are telling women who live in a tropical climate not to get mosquito bites. It is like basically saying that if you do [get Zika], it is your fault."*

The general perception was that women were given the responsibility of staying healthy and Zika free, which placed an undue burden on them, as Adela from Brazil, blatantly asked:

*"So if you have a child with microcephaly who is to blame?"*

Some women complained that government recommendations intruded into their personal lives. The public health establishment advised women to avoid sexual intimacy with their partners to circumvent an unexpected pregnancy that could lead to complications resulting from Zika virus infection. The recommendations to use chemical repellents and stay away from mosquito-infested locations created an enormous pressure on women to change their daily routines. Participants mentioned that those recommendations only targeted women and interpreted them as an unspoken gender bias, because all the burden of personal protection against mosquito bites was placed on women. According to Lorena F., the Brazilian government was not accountable for preventing or eradicating Zika:

*"I think, when the Minister [of Health] stated that women should not become pregnant, I found [it to be] an invasion. I think that he should be concerned with public policies that solve the [Zika] problem and not with recommendations about when women [should] get pregnant."*

Others, like Monica, perceived that the advice was relevant, but overburdened the individual:

*"I agree that they should inform people [about Zika], but at the same time I think that to ask to not have sexual relations, it is too much to ask."*

There are a number of factors that influence whether any person—men or women—may become infected with any type of mosquito-borne illness, but as suggested by interviewees, there was significant silent suffering by women facing the threat of exposure to the Zika virus. As Daniela, from Brazil, explained:

*"For any woman who lives in a place where Zika is part of everyday life, it is terrifying."*

### *3.2.2 Fear of the Unknown: "So I had the feeling of not knowing what it was"*

All participants stated that they experienced feelings of overall uncertainty that manifested as fear, insecurity, worry, and stress. Many of these feelings resulted from lack of knowledge about the Zika virus. This fear was prevalent among pregnant and non-pregnant women, those in the midst of planning to have children, as well as among women who lived in places where infected mosquitoes were present. The women interviewed stated that Zika was an unknown epidemic that caused innumerable questions to surface, such as how the virus could be contracted; whether or not they would be infected by the virus; the

medical impacts of Zika; and whether treatment would be available if they were infected. This scientific uncertainty about the virus increased their feelings of apprehension due to their perceived inability to properly protect themselves against mosquito bites. Rebecca R., from Miami, explained the anxiety Zika created:

*"It is such stress, you are all the time worried if there is a mosquito around you, and it is a constant focus of tension... you live in permanent tension and angst."*

The lack of medical knowledge about Zika also heightened feelings of insecurity. Some women did not trust the medical community's capability for tackling Zika. Those women were skeptical of the medical community's true knowledge of the virus, given the lack of agreement among medical practitioners. They were concerned with the suggested forms of combatting the mosquito through continuous application of chemical repellents, and doubted the alleged long-term health effects after infection. Several women perceived a lack of interest from their doctors regarding their concerns, which created a cycle of worry and stress, stemming from having a medical provider who was not adequately prepared to deal with the illness.

Fátima M. recounts the stress encountered when facing the ignorance of a physician who was not fully informed about how to diagnose and treat Zika:

*"I was more worried, definitely more worried because if the doctor, who was a doctor, didn't know what was going on, how was I, being just me, gonna feel right... "[the doctor said] 'I don't know if it is Zika, because I never treated Zika."*

The education levels of participants greatly influenced their attitudes towards Zika. Those interviewed with academic training or higher levels of education had a tendency to be consumed with high levels of worry and stress about the epidemic. Those women perceived the limitations in the educational information provided to the public, the inadequate government actions towards improving public health, and the inadequate medical care provided. Quite the opposite impact occurred among women with less education who accepted, without questions, information from medical providers or other health-related organizations, and exhibited a calmer outlook about their predicament. These two opposing perceptions can be surmised from the distinct outlooks of Rebecca R., from Miami, and Marina F., from Puerto Rico:

*"Well yeah, unfortunately, I know necessarily more than I ever wanted to know or thought that I would have to know in my life." (Rebecca R.)*

em>"The information that has circulated here is that the first three months are crucial for the baby if it does not come with microcephaly. That's the information that they gave us here and it satisfies me."  
(Marina F.)

### 3.2.3 Lifestyle Changes:

*"I had made my life so miserable not to have this [contract Zika] happen."*

The daily lives of the participants interviewed, as reflected in their social relationships and interactions with their partners, family members and children, were greatly impacted by Zika. Women described encountering obstacles in providing attention and care to children because they were preoccupied with their health, particularly if they were pregnant or attempting to conceive. They revealed that intimate relationships with partners suffered both emotionally and sexually, as the fear that Zika could be contracted via sexual contact caused a strain in the partnership. They showed resignation with respect to familial relationships by branching out of the nuclear family. Despite residing in the same city of their kinfolk, they would not visit them often, suggesting poor interpersonal interactions due to feelings of isolation and seclusion that resulted from fear of Zika. Marilyn G., for example, details her personal experience:

*"...It affected [the relationship] because [Zika] is a stress. You are worried, all of the time if there is or isn't a mosquito [present]... a constant focus of tension, the quality of life falls a lot because that affects the relationship. I had places that I would not go to... because I thought there could be mosquitoes."*

Women, in order to protect themselves from the threat of the virus, adopted behaviors that caused substantial changes in their social lives, identities, and personal wellbeing. These new behaviors caused deep disruptions in their psychosocial status. They often sprayed themselves with chemical repellents throughout the day and almost always wore long dresses and long sleeve shirts, despite residing in tropical climates with warm temperatures. One participant even relocated from Florida to Canada. A significant adjustment of what should be considered normal routine behavior was described by Mariana S.:

*"[I] bought a repellent and developed a routine that I put on every time I showered. I used to put on as if it were cream... like brushing your teeth and I would put it on every time I went outside. I tried to put on long clothes and not open shoes. I bought a product that I never used, to put on [my] clothes. [It] was very strong because, at the same time, these are chemicals to protect against Zika, but I'm also pregnant with a lot of chemicals all day long."*

On a personal level, participants described Zika as taking away the enjoyment of being a woman, especially when referencing motherhood and femininity. As Jessica A. stated,

*"I had become pregnant. This was a very happy moment. I wanted to show-off my belly. I wanted to wear dresses [but] I had to put aside my femininity because I had to protect myself."*

Many women expressed living in constant fear or anxiety of having to avoid or prevent mosquito bites from affecting their own health or that of their unborn child. A participant actually mentioned that she was not going to have any other kids after the epidemic and she didn't really get to enjoy her pregnancy.

Furthermore, some women completely rejected embarking on the journey of motherhood altogether, because becoming pregnant was a source of worry, pain, or stress. The concept of femininity also spills over into the emotional and sexual relationships women had with their intimate partners. By reflecting on

the external relationships that can be affected by Zika, participants gave us insight regarding how the virus shrouded their internal sense of self. The fact that participants felt the need to take drastic measures to avoid becoming infected subdued positive emotions surrounding pregnancy, motherhood, and femininity.

## Discussion

Few studies in the literature addressed the experiences of women indirectly affected and less vulnerable to the effects of the Zika epidemic. Most research published so far have primarily focused on women with children affected by Zika and/or living in areas where the Zika virus was widespread [16,17]. The discussion about infected women has concentrated on strategies to limit or prevent reproduction (i.e. abortion) in order to reduce the dissemination of the Zika virus [18, 19, 20]. Additionally, studies mainly address the attitudes, knowledge, and behaviors of pregnant women [17,18, 21]. In our study, women lived in diverse geographical regions and were from different nationalities and ethnicities, but similar socioeconomic backgrounds. Our study demonstrates how the Zika epidemic affects all women to some extent. It shows that the social effects of the epidemic affect more women than had been thought before and at deeper and psychosocial levels.

A number of women in our study perceived that the public health systems were placing an unfair responsibility for preventing health complications from Zika onto women who have limited ability to eradicate the vector. Many women stated that these measures were invasive, while creating the perception that they were the sole determinant of whether or not they contracted Zika. Their perception complements the findings of studies that identified two main frameworks relied upon by public health officials and the media to control the Zika epidemic: one focused on eradicating the vector (mosquito) and another on preventing microcephaly, both of which place the burden of prevention on women [22].

It has been claimed that Zika is a complex issue because women are not asked to protect their own health, but that of a child [23]. However, the Zika epidemic seems to be quite similar to other cases of global epidemics. For example, the policy and social responses to Zika were similar to the ones seen in the case of German measles or Rubella outbreaks, when the priority was also to protect future fetuses rather than women's bodies [24]. Because of the focus on preserving the life of the fetus, women have to deal with particular public health questions and costs [25]. The Rubella outbreaks also have in common with Zika the gender bias in making women responsible for most personal protective measures [26,27]. Thus, women appear to be disproportionately affected by epidemic outbreaks that have reproductive implications, even when they are only indirectly affected. Based on past experiences and our data, we argue that gender inequality and gender discrimination must be recognized and rendered visible in the public health emergency response against.

Lack of scientific evidence, such as the physiopathology of Zika and effective protective measures against the virus, caused a variety of questions to emerge during the early days of the epidemic. The lack of public and medical knowledge about Zika contributed to uncertainty and insecurity. A similar

phenomenon was evident during the 2009–2010 influenza pandemic, when individuals experienced confusion, anxiety, and increased risky behaviors because of the uncertainties [28]. Our findings suggest that the Zika epidemic led to similar anxiety among women who might not be directly impacted by Zika, but still experienced high levels of apprehension.

A number of studies reported that women who had lower education attainment levels were significantly less knowledgeable about the information produced for public consumption [21, 29]. Since many of our participants had higher levels of education, they had ample access to reliable sources of information and demonstrated high levels of scientific knowledge. Our study suggests that women with higher levels of education understood the limitations of the information, government actions, and medical care they received, which ended up producing higher levels of anguish and worry. The opposite seemed to be the case for women with lower levels of education.

It has been previously reported that women with children affected by Zika showed a significant loss of a sense of themselves [30]. A 2016 study that focused on pregnant women impacted by Zika found that women in Brazil and Puerto Rico, infected and not infected with the Zika virus, showed high levels of stress, anxiety, and depression [31, 32]. Our study adds to the literature by suggesting that even women who were not pregnant and only indirectly affected by Zika made decisions and arrangements to prevent infection that caused significant changes and disruptions to the very essence of their being.

Epidemic outbreaks, such as Ebola, create long-term distress in members of families of those who succumbed to the disease. Individuals experienced fear, anxiousness, numbness, and detachment [28]. Whole communities experienced fear, isolation, and suffering during or after an infectious disease epidemics [33, 34]. In our case, the women interviewed expressed, both directly and indirectly, suffering at the individual and family levels. The changes in their lives are significant, and to the best of our knowledge, we report it for the first time in relationship to the Zika epidemic.

Another profound impact of the Zika epidemic on the lives of many Latina and Brazilian women interviewed was the loss of femininity, because they had to cover their bodies to protect themselves against mosquito bites and could not dress as normal Brazilian or Latina women do. For those interviewees, their body was an important part of their femininity [35, 36, 37] and having to cover themselves prevented their ability to display freely their womanhood. They associated a sense of empowerment with the ability to exhibit one's body and/or pregnant body.

There were a number of limitations to our study. It had a 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), and women of a broader of educational and socioeconomic backgrounds. Additionally, we may not have comprehensively analyzed the effects of Zika on women's health due to our limited expertise in a few areas of public health and biological sciences.

However, through one-on-one interviews we developed a more in-depth understanding of the Zika epidemic impacts on women's daily lives. Our analysis of the impacts of Zika on a small sample of women provides input for larger survey studies. Further research may compare the experiences of women directly and indirectly affected by Zika in countries affected by the epidemic.

## **Conclusions**

The Zika epidemic highlights the fact that on a global scale women's health continues to encounter numerous barriers. Though participants in this study were of different nationalities and ethnicities, and most had good education levels, their actions and thoughts were embedded in common sociocultural norms. Therefore, our study shows the importance of considering cultural aspects and behaviors when implementing health prevention or protection measures to control epidemics. Financial, social, religious and cultural aspects are always involved in epidemics. The Zika epidemic was yet another lost 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 called for a broad spectrum of public health interventions.

## **Considerations**

### **Ethics approval and consent to participate**

The research protocol was approved by 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.

### **Availability of data and materials**

The datasets generated and/or analyzed during the current study are not publicly available due to the protection of individual privacy of participants but may be made available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare that they have no competing interests

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## Authors' contributions

All Interviews were conducted by Ana Rosa Linde. Ana Rosa Linde, Grace Furtado and Elisa Tristan-Cheever also transcribed the interviews. Dr. Linde double-checked all recording for accuracy. Dr. Linde collaborated with Eduardo Siqueira and Dr. Tristan-Cheever to create the structure of the node tree. Dr. Siqueira and Dr. Tristan-Cheever coded several interviews independently and discussed the node tree with Dr. Linde in several meetings before consensus was achieved. Dr. Linde was a major contributor in writing the manuscript. All authors read and approved the final manuscript

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# Table 1

Table 1. Sociodemographic Characteristics of the Women Interviewed

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