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## Women's lives in times of Zika: mosquito-controlled lives?

A vida das mulheres na era do Zika: vidas controladas por mosquitos?

Las vidas de las mujeres en tiempos de Zika: ¿vidas controladas por mosquitos?

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### Abstract

*Zika virus infection during pregnancy is a cause of congenital brain abnormalities. Its consequences to pregnancies has made governments, national and international agencies issue advices and recommendations to women. There is a clear need to investigate how the Zika outbreak affects the decisions that women take concerning their lives and the life of their families, as well as how women are psychologically and emotionally dealing with the outbreak. We conducted a qualitative study to address the impact of the Zika epidemic on the family life of women living in Brazil, Puerto Rico, and the US, who were affected by it to shed light on the social repercussions of Zika. Women were recruited through the snowball sampling technique and data was collected through semi-structured interviews. We describe the effects in mental health and the coping strategies that women use to deal with the Zika epidemic. Zika is taking a heavy toll on women's emotional well-being. They are coping with feelings of fear, helplessness, and uncertainty by taking drastic precautions to avoid infection that affect all areas of their lives. Coping strategies pose obstacles in professional life, lead to social isolation, including from family and partner, and threaten the emotional and physical well-being of women. Our findings suggest that the impacts of the Zika epidemic on women may be universal and global. Zika infection is a silent and heavy burden on women's shoulders.*

*Zika Virus Infection; Pregnancy; Women's Health; Sickness Impact Profile*

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## Introduction

In May 2015, the Pan American Health Organization (PAHO) issued an alert regarding the first confirmed Zika virus infection in Brazil. Subsequently, on February 1<sup>st</sup>, 2016, the World Health Organization (WHO) declared that the Zika virus was a public health emergency of great international concern <sup>1</sup>. Although the WHO downgraded Zika from a public health emergency to a “common threat” in November 2016, more than 50 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> that led governments, national and international agencies to issue advice and recommendations to safeguard women from infection <sup>6,7</sup>, women’s reproductive health has therefore been thrust into the limelight with the spread of Zika <sup>8,9</sup>.

While there has been great concern with the biomedical aspects of the disease <sup>5,10</sup>, little has been discussed about the psychological, social, and ethical aspects of the epidemic. Few studies were conducted to address the threatening effects of Zika in the daily lives of women worldwide or its social repercussions. Additionally, the real-life perceptions of how women are psychologically and emotionally dealing with the outbreak has to be documented yet. Therefore, we are undertaking an investigation on how the Zika outbreak affects women lives, particularly regarding their decisions on sexual behaviors and reproduction, such as their reproductive health, and their personal and family life.

In this pilot study, we analyzed the impact of the Zika epidemic on the lives of women living in Brazil, Puerto Rico, and US, who were indirectly affected by it to shed light on the social repercussions of Zika.

## Methodology

This is a qualitative study that collected data through semi-structured interviews with 18 women who live in different locations of Brazil, Puerto Rico, and US, and who were from a Brazilian, Hispanic and North American ethnicity. These women were recruited through a snowball sampling. Interviewees were selected according to socioeconomic position, residence, nationality and age. Interview guides were developed including topics such as women’s personal and family life, perceptions and knowledge of Zika, views on reproductive health and rights regarding the Zika syndrome. Interviews were conducted between October 2016 and June 2017 in English, Brazilian Portuguese, and Spanish. Transcripts of the interviews were analyzed for themes using the NVivo software (<https://www.qsrinternational.com/nvivo/home>) for qualitative data analysis. The research protocol was approved by the Institutional Review Board of the University of Massachusetts Boston under number 2016186.

## Results

### Participant characteristics

Table 1 shows the sociodemographic characteristics of the sample. The ages of the women varied between 22 and 41. A total of six women had long-term partners while 12 were married. Women resided in Florida, Massachusetts, and Washington DC (USA), Puerto Rico and different localities of Brazil. Brazilian, Hispanic and North American ethnicities were represented. There were nine participants who had undergone a recent pregnancy or were pregnant at the time of the interview, while there were four that were planning to become pregnant and three that did not want to become pregnant but lived in Zika affected locations. One participant was misdiagnosed with Zika while pregnant, another had a husband diagnosed with the virus during her pregnancy, and one participant had a positive diagnosis of Zika despite not being pregnant. All participants had at least college level education. Participants religious denominations included: Catholic, Evangelist, Spiritist, Agnostic, and Atheist.

**Table 1**

Sociodemographic characteristics of the women interviewed.

Characteristics	n
Age range (years)	
22-30	6
31-41	12
Ethnicity	
Brazilian	9
Hispanic	7
North American	2
Civil status	
Married	12
Long-term relationship	6
Maternity status	
Recently born baby	5
Pregnant	6
Planning to get pregnant	4
No plan to get pregnant	3
Residence	
Brazil	8
Washington DC (USA)	1
Massachusetts (USA)	3
Florida (USA)	3
Puerto Rico	3

## Impacts

We classified the impacts that Zika has had on the interviewed women at different levels (Table 2). The effects at personal level included the reduction of physical and emotional well-being, feelings of isolation, sadness, and uneasiness. The family life of interviewees was also affected. They repeatedly reported feeling isolated from their partners, children, parents, relatives and extended families. Elimination of leisure activities, such as social and outdoor activities, also contributed to social isolation. Reports of disruption in their social life and daily routines were common themes.

Participants started to use repellents on a constant basis and changed their dressing habits by wearing long sleeves and closed shoes, among others, which caused discomfort. At the professional level, women placed their careers at risk by giving up growth opportunities such as attending meetings and job-related travels, etc. They also felt isolated from colleagues because they tried to work from home or change occupation because of the fear of exposing themselves to Zika. Effects on the sexual and reproductive life include renouncing pregnancy or postponing their decision to motherhood, and in a few cases sexual abstinence as a form of protection.

Table 3 summarizes quotes that show the psychological stages found in the participants. All the changes and effects in varying aspects of their lives have produced consequences in their emotional health. The interviewees had a strong feeling of uncertainty and mistrust concerning unknown factors surrounding the Zika epidemic, which contributed to helplessness and distress. Fear, panic, concern, angst, and tension were also expressed. Sometimes, the women voiced feelings of sadness, responsibility, shame, failure, and even guilt because of the pressure of having a healthy child. Many participants conveyed a strong feeling loss of control of their own lives and reproductive decisions.

**Table 2**

Impact levels and themes from interviews.

Impact level	Themes
Personal	Decrease in mental and physical well-being Uneasiness Sadness Low self-esteem
Family	Isolation from partner and children Sexual abstinence Isolation from family, parents, relatives
Social	Isolation from friends and social activities
Professional	Harm, at risk of Isolation Work from home Loss of opportunities Job change
Reproductive	Postponement Renunciation
Daily life	Increase of use of repellent Long sleeve clothes, etc. Changes in the home environment Reduction or elimination of social activities Elimination of leisure activities

**Table 3**

Quotes about emotions felt by women.

Emotions felt	Quotes
Uncertainty	<i>"So, I had the feeling of not knowing what it was... I was protecting myself from a thing I did not know exactly what it was, what do I have to protect myself for? It was a very tense experience..."</i>
Helplessness, distress	<i>"How do you protect yourself from a mosquito? There is no way... no possible way... Mosquitos are everywhere..."</i>
Fear, panic, concern, angst, tension	<i>"It is such a stress, you are worried all of the time if there is a mosquito around you, and it is a constant focus of tension... you live in permanent tension and angst"</i>
Sadness	<i>"I was finally pregnant, it was supposed to be the happiest time for a woman, and I just felt a tremendous sadness for all the circumstances..."</i>
Shame, guilt, failure, pressure	<i>"I felt I had failed at doing what I had to do... and it's like... OK you are telling women who live in a tropical climate not to get mosquitos bites, it is like basically saying that it is your fault [if you get Zika]..."</i>
Loss of control	<i>"And I have to plan my reproductive life according to the vital cycle of a mosquito... This is crazy, it is absurd"</i>

## Discussion

Our study shows how the Zika infection is a silent and heavy burden on women's shoulders. No women are exempt from the impacts of Zika, considering that the women we interviewed have relatively comfortable socioeconomic positions. They were of diverse religious denominations, mixed nationalities and cultures, but shared similar behaviors and effects. Some studies approached the beliefs and/or actions of pregnant women during the epidemic within a homogenous sample collected in certain

countries<sup>9,11,12</sup>. Our findings suggest that the impacts of the Zika epidemic on women might be universal and global – and that perhaps many important ones have been so far ignored in the literature.

The coping strategies that women are adopting to live in times of Zika seem to be posing obstacles to their professional careers, isolation from their family, and harm to their emotional and physical well-being. Women's narratives indicate that they are sacrificing a lot for motherhood and to have a healthy baby. They placed their careers at risk by giving up opportunities that could involve exposure to mosquito-infested environments. They also withdrew from family, social and leisure activities to avoid exposure to the Aedes, as a result increasing the likelihood of social isolation.

The impacts on the sexual and reproductive life are concerning. Some interviewees decided to renounce or postpone their decision to become pregnant, which was also reported by women in Brazil<sup>13,14</sup> and in Puerto Rico<sup>15</sup>. Additionally, participants disclosed sexual abstinence during pregnancy, negatively affecting their emotional relationship with the partner.

All the changes in varying aspects of their daily lives have produced adverse emotional consequences for the interviewed women. For example, a change in dressing up habits resulted in women choosing to wear long sleeves in hot climates. Similar protection strategies can be seen in one study<sup>9</sup>, but it does not show their effect on the psychological status of women.

Thus, the Zika epidemic is taking a heavy toll on the emotional well-being of women. On the one hand, the presence of the virus created mixed and contradictory feelings of joy and sadness during pregnancy, because they could not fully enjoy their pregnancy, or had to renounce the joy of maternity. On the other hand, they felt responsible to avoid Zika contraction when, in reality, it is very difficult for them to control the mosquito.

This heavy toll is clearly and strongly stated by one woman, who complained: “...I have to plan my reproductive life according to the vital cycle of a mosquito. This is crazy, it is absurd”.

## Contributors

A. R. Linde contributed with the research design, implementation, analysis of the data and manuscript elaboration. C. E. Siqueira contributed with the research design and revision of the manuscript.

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## Resumo

*A infecção pelo vírus Zika durante a gravidez é causa de anomalias congênitas do sistema nervoso central do feto. As graves consequências gestacionais fizeram com que governos nacionais e agências internacionais emitissem conselhos e recomendações para as mulheres. Existe uma necessidade clara de investigar de que maneira a epidemia de Zika afeta as decisões das mulheres sobre suas próprias vidas e de suas famílias, e de como as mulheres estão lidando psicológica e emocionalmente com a epidemia. Realizamos um estudo qualitativo para avaliar o impacto social da epidemia de Zika na vida familiar das mulheres no Brasil, Porto Rico e Estados Unidos. As mulheres foram recrutadas através da técnica de “bola de neve”, e os dados foram coletados com entrevistas semiestruturadas. O artigo descreve os efeitos sobre a saúde mental e as estratégias das mulheres para enfrentar a epidemia do vírus Zika. O vírus está tendo um impacto pesado no bem-estar emocional das mulheres. Elas estão lidando com sentimentos de medo, desamparo e incerteza, ao tomar precauções drásticas para evitar uma infecção que afeta todas as áreas de suas vidas. As estratégias de enfrentamento envolvem obstáculos na vida profissional, levam ao isolamento social, inclusive em relação à família e ao companheiro e ameaçam o bem-estar emocional e físico das mulheres. Nossos achados sugerem que os impactos da epidemia de Zika sobre as mulheres podem ser universais e globais. A infecção pelo vírus Zika põe uma carga pesada e silenciosa nos ombros das mulheres.*

*Infecção pelo Zika Virus; Gravidez; Saúde da Mulher; Perfil de Impacto da Doença*

## Resumen

*La infección por el virus del Zika durante el embarazo es una causa de anomalías cerebrales congénitas. Sus consecuencias para los embarazos han hecho que los gobiernos, las agencias nacionales e internacionales emitan consejos y recomendaciones para las mujeres. Existe una clara necesidad de investigar cómo el brote de Zika afecta las decisiones que toman las mujeres con respecto a sus vidas y la de sus familias y también cómo las mujeres están lidiando psicológica y emocionalmente con el brote. Llevamos a cabo un estudio cualitativo para abordar el impacto de la epidemia de Zika en la vida familiar de las mujeres que se vieron afectadas por la enfermedad, y que viven en Brasil, Puerto Rico y los EE.UU., para arrojar luz sobre las repercusiones sociales del Zika. Las mujeres fueron reclutadas a través de la técnica de muestreo de bola de nieve y los datos fueron recolectados a través de entrevistas semiestruturadas. Describimos los efectos en la salud mental y las estrategias de afrontamiento que las mujeres usan para lidiar con la epidemia de Zika. La enfermedad está afectando mucho el bienestar emocional de las mujeres. Están enfrentando sentimientos de miedo, impotencia e incertidumbre tomando precauciones drásticas para evitar infecciones que afectan todas las áreas de sus vidas. Las estrategias de afrontamiento representan obstáculos en la vida profesional, conducen al aislamiento social, incluso de la familia y la pareja, y ponen en peligro el bienestar emocional y físico de las mujeres. Nuestros hallazgos sugieren que los impactos de la epidemia de Zika en las mujeres pueden ser universales y globales. La infección por Zika es una carga silenciosa y pesada para los hombros de las mujeres.*

*Infeción por el Virus Zika; Embarazo; Salud de la Mujer; Perfil de Impacto de Enfermedad*

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