WOMEN’S FERTILITY DECISION-MAKING AS A RESPONSE TO THE ZIKA VIRUS EPIDEMIC IN FORTALEZA, BRAZIL

A DISSERTATION

SUBMITTED ON THE TWELFTH DAY OF FEBRUARY 2020

TO THE DEPARTMENT OF GLOBAL COMMUNITY HEALTH AND BEHAVIORAL SCIENCES

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS OF THE SCHOOL OF PUBLIC HEALTH AND TROPICAL MEDICINE OF TULANE UNIVERSITY

FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY/ PUBLIC HEALTH/ SCIENCE

BY

JENI STOLOW

APPROVED: " __________"

CARL KENDALL, PhD; February 18, 2020

ARACHU CASTRO, PhD; February 18, 2020

CHRISTOPHER DUNN, PhD; February 18, 2020

LINA MOSES, PhD; February 18, 2020
TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION .............................................................................................................. 6

1.1 SETTING ........................................................................................................................................ 6

1.2 TOPIC SELECTION RATIONALE ................................................................................................. 6

1.3 THE STUDY ..................................................................................................................................... 7

CHAPTER 2: BACKGROUND ............................................................................................................... 10

2.1 ZIKA VIRUS AND THE EPIDEMIC .......................................................................................... 10

2.1.1 Zika Virus ................................................................................................................................. 10

2.1.2. ZIKV Technical Efforts .......................................................................................................... 14

2.2 BRAZIL ........................................................................................................................................ 15

2.2.1. Geographic and Demographic Considerations ...................................................................... 15

2.2.2 Healthcare: Sistema Único de Saúde ...................................................................................... 18

2.2.3. Economic Considerations ....................................................................................................... 21

2.3 ZIKV RECOMMENDATIONS AND BEST PRACTICES ............................................................. 22

2.3.1. World Health Organization .................................................................................................... 22

2.3.2. The Brazilian Ministry of Health .......................................................................................... 23

2.3.3. Brazil’s Role in the ZIKV Epidemic ....................................................................................... 24

2.3.4. Best Practices in Outbreak Communication ......................................................................... 25

2.3.5. Best Practices in Health Communication .............................................................................. 26

2.4 CHALLENGES TO ADHERING TO RECOMMENDATIONS ................................................... 27
Table of Contents

2.4.1. Recommendation 1: Vector-based Prevention ................................................................. 28

2.4.2. Recommendation 2: Pregnancy avoidance and reproductive health counseling........... 32

2.4.3. Contraceptive Utilization .................................................................................................. 33

2.4.4. Policy Considerations (Abortion and Health Insurance) ............................................. 34

2.4.5. Reproductive and Fertility Decision-Making ................................................................. 36

2.4.6. Cultural Considerations: Traditional Gender Roles .................................................... 37

2.4.7. Motherhood .................................................................................................................. 39

2.5. THEORETICAL CONSIDERATIONS AND CONCEPTUAL FRAMEWORK ............ 41

2.5.1. Theory of Gender and Power ......................................................................................... 42

2.5.2. Stratified Reproduction ................................................................................................. 45

2.5.3. Conceptual Model of Fertility Decision-Making as a Response to The ZIKV Epidemic ................................................................. 47

2.6. STUDY SETTING ............................................................................................................ 49

2.6.1. ZIF Study ................................................................................................................... 51

2.6.2. The Study Environment .............................................................................................. 53

2.6.3. The Researcher ............................................................................................................ 54

CHAPTER 3: METHODS ......................................................................................................... 55

3.1. THE STUDY .................................................................................................................... 55

3.2. TIMELINE ....................................................................................................................... 56

3.3. SUPERVISION AND STUDY TEAM ............................................................................ 57
3.4. RESEARCH QUESTION AND PROPOSITIONS .................................................. 58

3.5. SAMPLING ...................................................................................................... 61

3.6. METHOD ONE: RAPID ANTHROPOLOGICAL ASSESSMENT ......................... 62

  3.6.1. RAA: The Guide .................................................................................. 64

  3.6.2. RAA: In-depth, Semi-Structured Interviews ............................................. 66

  3.6.3. Managing and Analyzing Data ................................................................. 68

  3.6.4. RAA: Analysis .................................................................................... 68

3.7. METHOD TWO: CASE STUDIES .................................................................. 70

  3.7.1. Case Study Analysis ............................................................................ 71

3.8. TRIANGULATION .......................................................................................... 72

  3.8.1. Observations ....................................................................................... 73

  3.8.2. Informational conversations ................................................................. 73

3.9. OUTCOMES OF ANALYSIS ........................................................................ 75

CHAPTER 4. Women’s Perceptions of ZIKV Prevention Recommendations: A Tale of Two
Cities Within Fortaleza, Brazil (Manuscript 1) .................................................... 76

CHAPTER 5. Fertility Decision-Making During the ZIKV Epidemic: Where is the decision?
(Manuscript 2) ....................................................................................................... 103

CHAPTER 6. Case Studies of Zika’s Forgotten Women (Manuscript 3) ....................... 129

CHAPTER 7: DISCUSSION .................................................................................... 164

  7.1. SUMMARY .............................................................................................. 167
CHAPTER 8: CONCLUSION ................................................................. 169

8.1 ZIKV SPECIFIC RECOMMENDATIONS ........................................... 169

8.2. GENERAL EPIDEMIC RECOMMENDATIONS .................................... 172

8.3. LIMITATIONS ........................................................................... 173

REFERENCES ..................................................................................... 175

APPENDIX ......................................................................................... 192

Figure 1: WHO’s Timeline of ZIKV Recommendations and Discoveries. .............. 192

Figure 2: Conceptual Model of Fertility Decision-Making as a Response to The ZIKV
Epidemic .......................................................................................... 194

Figure 3: Socioeconomic Class in Brazil .................................................... 195

Figure 4: Fieldworker Training ................................................................ 196

Figure 5: RAA Guide .......................................................................... 197
CHAPTER 1: INTRODUCTION

1.1 SETTING

Zika virus (ZIKV) was first documented in Uganda in 1947 yet gained international attention when it reappeared at an epidemic level in Brazil in 2015. ZIKV is a flavivirus transmitted primarily via *Aedes aegypti* mosquitoes with adverse health outcomes most severely impacting pregnant women and fetuses (World Health Organization [WHO], 2018a). The World Health Organization declared a Public Health Emergency of International Concern for ZIKV in February 2016. This declaration followed the Brazilian Ministry of Health’s State of Emergency issued in November 2015 (WHO, 2016; Ministério da Saúde, 2015a). The Brazilian State of Emergency was the result of a drastic increase in the incidence of microcephaly in the Northeast of Brazil (Ministério da Saúde, 2015b).

Fortaleza is the capital city of the state of Ceará, found in the Northeast Region of Brazil. Ceará has experienced significant exposure to ZIKV with 3,495 suspected cases of ZIKV reported through 2017 (Ministério da Saúde, 2018). In 2018, there was a decline in suspected cases of ZIKV in Ceará (n=590), although the distribution of cases has spread to 41.3% of the municipalities in the state (Secretaria da Saúde do Estado do Ceará, 2019). Approximately 65.9% of those ZIKV cases were reported among 20 to 39-year-olds – a concern for women of reproductive age (Secretaria da Saúde do Estado do Ceará, 2019).

1.2 TOPIC SELECTION RATIONALE

The World Health Organization recommends three main forms of ZIKV prevention: (1) protection from mosquito bites, (2) utilization of condoms to avoid sexual transmission of the disease, and (3) reproductive health counseling with healthcare providers (WHO, 2017a). The
Brazilian Ministry of Health has chosen to promote ZIKV prevention almost exclusively through conventional and ineffective vector control methods developed over the past two decades for *Aedes aegypti*. Aside from vector control, health promotion advised women to avoid pregnancy during the epidemic (Ministério da Saúde, 2017). Messages related to reproductive health counseling and utilization of condoms were delayed, not well advertised, and did not acknowledge men’s role in the spread of ZIKV. Vector control information was also one-sided, as it mainly targeted women. Health recommendations made during the epidemic appear to have been made with haste and without consideration of local context or the basics of health promotion. ZIKV messages were promoted in simple declarative announcements on radio, television, and in news which focused on microcephaly (Adriano et al., 2016). This dissertation focuses on these issues through the viewpoint of women in Fortaleza: how did they perceive these prevention recommendations, the feasibility of performing these behaviors, and act on them, especially the recommendation focused on reproduction.

1.3 THE STUDY

As a response to the ZIKV threat in Fortaleza, Brazil, the Zika in Fortaleza (ZIF) study was created by researchers at the Federal University of Ceará, based in Fortaleza. ZIF or “Zika em Fortaleza: respostas de uma coorte de mulheres entre 15 e 39 anos” (“Zika in Fortaleza: Response of a cohort of women aged 15-39”) is a cohort study led by principle investigator, Dr. Ligia Kerr, MD, MPH, Ph.D. and co-PI Dr. Carl Kendall, MA, Ph.D. The ZIF study was funded through CNPq(440778/2016-6), CAPES(88881.130806/2016-01; 88887.130795/2016-00), and FUNCAP(3898920/2017). The cohort study began recruitment in 2016 and followed 1,472 women recruited from four public clinics in Fortaleza. The study is comprised of three
components: a quantitative survey; a laboratory component; and a qualitative component which includes a Rapid Anthropological Assessment (RAA). This dissertation was nested within the ZIF study and served as a qualitative complement to the cohort study, building on the previous RAA to advance knowledge of women’s responses to ZIKV. Collaboration included participation in meetings with the study team in Fortaleza and reviewing interviews conducted by the team. In addition, I conducted my own interviews and a series of case studies. During this process I also explored, with the PIs and team on the ground, additional research topics and foci included in the ZIF study’s other components. I warmly acknowledge the contributions of the whole ZIF team in my own work and their sharing of their research in the development of this dissertation.

This study utilized qualitative methods to create a deeper understanding of how women experienced this epidemic. Social science research began late in the epidemic and continues to constitute a small proportion of research studies on ZIKV in Brazil. This lack of social science research has created gaps in the literature including under-explored topics such as: how ZIKV prevention recommendations were perceived, how contextual factors played a role in the spread of ZIKV, and what ZIKV symbolizes for those most impacted. This study was meant to serve as an opportunity for women to discuss their understanding of ZIKV, including perceptions toward ZIKV prevention, and their experiences with ZIKV. This study’s methods included an iteration of the cohort’s ZIF Rapid Anthropological Assessment and a series of case studies.

The overall goal of this study sought to understand:

- What role does ZIKV play in the lives of women and children in Fortaleza, especially as it pertains to the ZIKV prevention recommendations related to pregnancy and
fertility decision-making made by Brazilian health authorities during the epidemic?

- Furthermore, how does ZIKV continue to play into the lives of women and children most severely impacted by ZIKV related adverse health outcomes?

**Key questions** were developed to help organize the qualitative guide and research strategy:

1. **ZIKV Recommendations and Response**
   What do women know about the ZIKV health messages and recommendations? What are women’s perceptions about the feasibility of ZIKV recommendations? What do they actually do to prevent ZIKV infection?

2. **Fertility Decision-Making during ZIKV**
   Did, and are women currently, modifying their fertility decisions due to the ZIKV epidemic in Brazil? Why or why not?

3. **Adverse pregnancies and children born with CZS in Fortaleza**
   What were the experiences of women who had adverse pregnancies associated with ZIKV and their experiences raising children with Congenital Zika Syndrome?

The findings of this dissertation have been separated into three manuscripts, each paper corresponding to one of the key research questions. Manuscript 1 of this study discusses women’s perceptions of ZIKV prevention recommendations; Manuscript 2 relates to women’s fertility decision-making during the ZIKV epidemic, and; Manuscript 3 includes a series of case studies documenting the experiences of women and children heavily impacted by ZIKV.
CHAPTER 2: BACKGROUND

2.1. ZIKA VIRUS AND THE EPIDEMIC

2.1.1 Zika Virus

Zika virus (ZIKV) is a vector-borne flavivirus transmitted primarily via Aedes aegypti mosquito, perinatally, or through sexual contact between partners (Centers for Disease Control and Prevention [CDC], 2018a; World Health Organization [WHO], 2018a). As of August 2019, 86 countries and territories have reported confirmed cases of ZIKV since the initial outbreak in 2015. Of those areas, 27 countries and territories have reported confirmed cases of congenital defects associated with the ZIKV infection (Pan American Health Organization [PAHO], 2018). According to the World Health Organization and the Centers for Disease Control and Prevention, most cases (80-90%) manifest as asymptomatic (CDC, 2018a; WHO, 2018a). After the bite of an infected female Aedes aegypti mosquito, symptomatic ZIKV cases typically present with generic symptoms such as a red skin rash, fever, muscle pain, joint pain, headache, and malaise. Symptoms usually last for 2-7 days, after an incubation period of approximately 4-10 days (CDC, 2018a; WHO, 2018a). Asymptomatic cases can be problematic, as patients may not seek testing or medical care. Asymptomatic cases can also lead to unknown sexual or vertical transmission of ZIKV. Due to the similarity of symptoms, duration of symptoms, timeline of infection, and similar incubation periods, there is great difficulty in differentiating symptomatic cases of ZIKV, dengue, and chikungunya. Epidemics of which, as in Fortaleza, can run concurrently. Serological laboratory testing additionally has difficulty differentiating diagnoses (Azeredo, 2018; Braga, 2017; CDC, 2017; Christofferson, 2016). Currently, there is no treatment or cure for ZIKV.
The outcomes of ZIKV infection that have drawn the most attention are the possibilities of fetal death or contracting a neuropathogenic ailment such as microcephaly or Guillain-Barre Syndrome. Guillain-Barre Syndrome is a condition that manifests as paralysis to a person’s peripheral nervous system, which can be fatal (WHO, 2017). ZIKV has shown to be a trigger for Guillain-Barre Syndrome, yet further research is required to understand the mechanisms by which this occurs. While the full panoply of effects of ZIKV infection have yet to be determined, the main outcome of interest, ZIKV-associated birth defects, has been defined and recorded differently across countries.

According to the Centers for Disease Control and Prevention, microcephaly is defined as a head circumference measurement less than 2 standard deviations below the average of babies of the same age and sex (CDC, 2018b). Microcephaly is related to poor brain growth, developmental disabilities, and death. Microcephaly can present in the fetus at the end of the second trimester (at approximately 24-28 weeks), at time of birth, or postnatally (CDC, 2018b). The World Health Organization states: “Many babies born with microcephaly may demonstrate no other symptoms at birth but go on to develop epilepsy, cerebral palsy, learning disabilities, hearing loss, and vision problems” (2018b). Microcephaly is just one of the possible congenital abnormalities associated with the vertical transmission of ZIKV infection - the umbrella of these possible outcomes has been labeled Congenital Zika Syndrome (CZS). Cases of CZS and microcephaly can range from mild to severe, and some cases present without any abnormal development through life. Possible outcomes associated with CZS include microcephaly, hydrocephaly, partially collapsed skull, decreased brain tissue, subcortical calcifications, congenital contractures, arthrogryposis, hypertonia, seizures, deafness, blindness, brainstem
dysfunction, motor abnormalities, and possible autism (Adibi, Marques, Cartus, & Beigi, 2016; Adriano et al., 2016; CDC, 2018b; Pessoa, 2018; Vianna, 2019).

A study by the Centers for Disease Control analyzed the birth outcomes of 1,297 pregnancies in which the woman was infected by ZIKV in her first trimester. The study found that birth defects were reported in 15% (95% CI = 8%-26%) of fetuses/infants of completed pregnancies (CDC, 2018c). A study by the Oswaldo Cruz Foundation (Fiocruz) in Brazil conducted a similar study, with the goal of analyzing the birth outcomes of children born to women who tested positive for ZIKV during any point in the pregnancy. The study concluded that of 117 live infants born to 116 ZIKV-positive women, 42% were found to have Zika associated congenital defects (Brasil, 2016). No follow up studies have been conducted to see if delayed negative birth outcomes were encountered. It is possible that these findings underreport the actual percentage of children born with ZIKV related anomalies if follow-up of the children affected, and the broader birth cohort, is not conducted. Additional adverse effects of ZIKV surrounding pregnancy include infertility, pain during pregnancy, miscarriage, low newborn birthweight, fetal growth restriction, stillbirth, and perinatal death (CDC, 2018c). It should also be noted that emotional trauma for the mother can be an associated secondary outcome connected to any of the previously mentioned outcomes (Duarte, 2016).

It was an initial rise of microcephaly cases that alerted Brazilian health authorities as to a potential health emergency. Northeastern Brazilian health authorities noted a spike in microcephaly incidence throughout 2015, leading to a Declaration of Emergency by the Brazilian Ministry of Health in November 11, 2015 (Ministério da Saúde, 2015a; Ministério da Saúde 2015b). The speed of spread and accumulation of cases throughout the region prompted the World Health Organization to declare a Public Health Emergency of International Concern
(PHEIC) on February 1, 2016 (WHO, 2016). The epidemic continued to grow, then steadily decline, eventually persuading the WHO Director-General to end the PHEIC on November 18, 2016 (WHO, 2017b). A full timeline of ZIKV recommendations and discoveries can be found in Figure 1: Timeline of ZIKV Recommendations and Discoveries.

According to the latest Pan American Health Organization report from January 4, 2018, there have been 223,477 confirmed cases of ZIKV reported since the epidemic began in 2015. Of those cases, 137,288 were reported in Brazil (approximately 61.4%) (Pan American Health Organization [PAHO], 2018). Since its outbreak in 2015, there have been 3,720 CZS cases, with 2,952 of those cases found in Brazil (approximately 79.4%) (PAHO, 2018). It should be noted that this WHO and PAHO monitoring of ZIKV has not been updated since this latest report, thus not reflecting incidence in 2018 and 2019. Reduced global surveillance and monitoring is associated with factors such as: epidemic decline, competing infections, lack of healthcare system strengthening, as well as the absence and cost of effective testing (Center for Reproductive Rights, 2018; Gómez, Perez, & Ventura, 2018; Wurth, 2017).

Gaps in vector surveillance and the lack of documentation of asymptomatic cases suggest these numbers are a misrepresentation of the true scope of ZIKV. Without symptoms, it is unlikely that the individual would go to a healthcare facility and even less likely they would be tested for ZIKV. Routine testing of pregnant women or testing for other diseases may have been the source of data on these asymptomatic cases. It is moreover plausible that these case numbers do not reflect the true number of symptomatic cases of ZIKV, especially cases that presented with mild symptoms. Studies have shown that surveillance systems in place throughout Latin America have a low probability of detecting outbreaks of ZIKV and trends in CZS (Bautista & Herrera, 2018). The February 2018 World Health Organization ZIKV Classification Table has
deemed Brazil to still be at a Category 2, meaning the risk of contracting ZIKV is still significant and there is still a potential for another outbreak (WHO, 2018b). There have been no updates or changes made to this Classification Table since 2018.

2.1.2. ZIKV Technical Efforts

With the decline of ZIKV cases worldwide, scientific effort has moved from outbreak response to clinical, technical, and research activities. The 2018/2019 World Health Organization Blueprint of Priority Diseases as placed ZIKV on the priority list for focused research and design efforts toward understanding and containing the virus (WHO, 2019a). Most of the contemporary research is focused on understanding the pathogenic and microbial components of ZIKV, as well as the development and trials of a ZIKV vaccine. The World Health Organization has created a Vaccine Development Pipeline Tracker to assist researchers in following ZIKV vaccine candidates through their conception, trial phases, and results (WHO, 2019b). As of December 2019, there are 16 trials stemming from government, academic, and industry sponsors – two of these trials have advanced to a Phase 2 trial (WHO, 2019b). Phase 3 human trials have not yet been completed as the low incidence of ZIKV limits the ability of trials to assess the vaccine’s protective effects. While vaccines bring substantial promise, they will never achieve 100% coverage or effect, and given consequences of infection in pregnant women, it is still essential to understand the infrastructural, social, and behavioral components of ZIKV infections if a more successful prevention strategy is to be mounted.
2.2. BRAZIL

2.2.1. Geographic and Demographic Considerations

Brazil is a vast country, (8,358,140 m$^2$) with 207.65 million people, making Brazil the fifth largest country in both land mass and population (World Bank, 2017). Brazilians for official government purposes use a system of racial classifications. As in the U.S., such classifications do not identify biological race, but rather a mix of criteria including skin color and ethnicity. According to the latest Census Data from 2010, Brazil is composed of 47.7% White (Branco), 43.1% Mulatto/Multiracial (Pardos), 7.6% Black (Pretos), 1.1% Asian (Amarelos), and 0.4% Indigenous (Indígenas) peoples (Instituto Brasileiro de Geografia e Estatística, 2010). While religious affiliation is changing rapidly, in 2010 religious affiliation is estimated to be 65% Catholic with the remainder comprised of mostly Evangelical faith (Instituto Brasileiro de Geografia e Estatística, 2010). There are additionally a number of Afro-Brazilian faiths which participants may assert are their religious identifications or may practice them concurrently with Catholicism.

Brazil’s territories are divided into five substantially different geographic regions: North, Northeast, South, Southeast, Central West, and six including Federal District (Brasília). The regions have important differences with respect to topology and climate, farming and agriculture, and culture as the regions experienced varying histories of European and African settlement. With vast industrialization, urbanization, agricultural, petroleum, mining, and hydroelectric resources Brazil is considered by the World Bank to be a middle-income country (World Bank, 2017).

Although Brazil has experienced periods of rapid economic growth in the 20th and 21st centuries, its problems with national income inequality have yet to improve with the same speed.
As a country with a long history of religious and social conservatism, Brazil also suffers substantial gender inequality. Brazil’s Global Gender Gap places it in the lower quartile of countries (95\textsuperscript{th} out of 149 countries) demonstrating large financial inequalities between men and women (World Economic Forum, 2018). According to the 2019 United Nations’ Human Development Report, the Human Development Index (HDI) of Brazil is 0.761, the Human Development Index adjusted for Inequality (IHDI) is 0.574, the Gender Development Index (GDI) is 0.995, and the Gender Inequality Index is 0.386 (United Nations Human Development Report, 2019). These demographic estimates demonstrate that although Brazil is heading in a direction of becoming a high-income country, the inequity and inequality throughout its borders are still substantial.

Regional disparities between the northern and southern regions are considerable, with inequity and underlying socioeconomic differences perpetuating extreme differences in poverty, access to healthcare, and subsequent health outcomes (Victora et al., 2011). The North and Northeast of Brazil are more rural, experience more poverty, have poorer infrastructure, low economic growth, low levels of literacy, and worse health outcomes with respect to the wealthier South and Southeastern regions of Brazil (Global Burden of Disease [GBD] 2016 Brazil Collaborators, 2018).

Regionalism in this dissertation does not just refer to a geographic location, but the social, historical, economic, and traditional practices that bind an identity. The nordestinos, or people of the Northeast are mostly comprised of decedents of colonization, slavery, and indigenous roots. It is for this reason that the demographics of the region are comprised of more mulatto and black people than the southern areas of Brazil. This history of indigenous tribes and slavery has created stereotypes and prejudice against the Northeast (Blake, 2011). The area of
this study, Ceará, is often referred to as the “sertão”, making its people the “sertão nordestinos”. The “sertão” is one of the largest territories in Brazil as it extends across the states of Alagoas, Bahia, Ceará, Paraíba, Pernambuco, Piauí, Rio Grande do Norte, and Sergipe. This is a unique Northeastern identity as it was the first interior region in Brazil to be colonized, therefore encapsulating generations of influence from mostly indigenous and Portuguese ancestors (Blake, 2011). The Northeast territory covers approximately 20% of Brazil’s landmass, 25% of the total population, and produces at least 20% of total agriculture. This is a vast, dry, hot region with the highest rates in both poverty and unemployment.

Great economic and technological growth has placed Brazil in a position of modernization, capitalization, and assimilation to high-income nations. While the north and northeast areas host farms and rural populations, the southern regions of Brazil host large metropolitan areas such as Rio de Janeiro and São Paulo which have become international hubs of travel, finance, and technology. The speed in which these metropolitan areas have grown is adding to the growing divide between the southern areas and the northern areas. The southern areas are modernizing, increasing use of technology, building skyscrapers and expanding their urban planning, whereas the northern areas are home to heat, large amounts of rainfall, close proximity to Amazon rainforest, and lack of infrastructure such as water sanitation, water storage, clean water, garbage disposal, and sewage.

The initial ZIKV outbreak started in the Northeast, with initial cases and scientific studies evaluated by Northeastern medical staff and researchers (Campos, Bandeira, & Sardi, 2015; Faria et al., 2016; Ventura, 2016; Zanluca et al., 2015). Skepticism around nordestinos’ ability to adequately handle the new epidemic and track cases of ZIKV and microcephaly bombarded the northeast from outsiders and southern critics (Diniz, 2016a; Stolow & Castro, 2018). Diniz
(2016) writes in her book *Zika: From the Brazilian Backlands to Global Threat* “Skepticism about the [case] numbers also reflected skepticism about the idea that Northeast Brazil can produce serious science. Not only were these Northeasterners mistrusted because of their geographic origins; many were also the target of suspicion because they were clinicians, professors, and healthcare providers lacking the usual scientific credentials listed in the bios published in high-impact international journals…” (p.6). Although this dissertation is critical of the Brazilian and international authorities’ response to the ZIKV epidemic, it should be noted that this criticism does not extend to the Brazilian epidemiologists, clinicians, and virologists (with or without those credentials) that first identified the ZIKV epidemic in Brazil, the increase in microcephaly, and demonstrated the association of microcephaly with ZIKV infection (Campos, Bandeira, & Sardi, 2015; Faria et. al, 2016; Ventura, 2016; Zanluca et. al, 2015).

2.2.2 Healthcare: Sistema Único de Saúde

Brazil’s universal healthcare system, *Sistema Único de Saúde* (SUS), was established in 1988, and provides public healthcare to all Brazilian citizens. In addition to the public sector, there exists a strong private health sector with opt-in private health insurance. Approximately 75% of healthcare provided in Brazil is from the public sector, with the other 25% of services provided by the private sector (Souza, Malta, Franca & Barreto, 2018). Brazilians typically utilize a mix of public and private services, and most physicians will work in both public and private settings. Most hospital beds and tertiary care in Brazil is provided by the public sector, while the private sector is primarily utilized for specialized care or by those of the wealthiest socioeconomic classes. A 30 year longitudinal study of SUS by Castro et al. found that the northern regions of Brazil include the largest proportion of the population who solely access the
public-sector and have continuously had the lowest access to private insurance, as compared to the more affluent southern areas (Castro et al., 2019). Furthermore, northern residents make up the largest proportion of social program utilizers (Rosendo, 2017).

Brazil’s universal health system has been working to provide services to its massive population who may not otherwise have access to healthcare. Improvements attributed to SUS’s widespread rollout include lowered rates of maternal morbidity and mortality, child morbidity and mortality, congenital transmission of disease, and unintended pregnancy rates (Leal et al., 2018). Overall increases in life expectancy, decreases in mortality due to transmissible disease, improved access to medications and quality healthcare have additionally been attributed to SUS’s formation (Souza, Malta, Franca & Barreto, 2018). These improvements are not solely due to SUS – there have been economic improvements, increases in education, better housing infrastructure, and social programs geared toward improving maternal and child health outcomes. Although SUS has created better access and more cohesive care for Brazilians, the system is currently undergoing rapid change, reorganization, and funding difficulties (Massuda et al., 2018).

SUS also includes a health data network (DataSUS) that connects health resources and information throughout Brazil. It was because of the interconnectedness of the singular healthcare system that researchers, scientists, and medical professionals were notified of increase case rates of microcephaly. This national reporting mechanism allows Brazilian health officials to have a homogeneous surveillance system for diseases, outbreaks, and vectors such as mosquitos. This unified surveillance network aided in the organization and rollout of a national strategy to combat ZIKV. Emergency responses and the dissemination of information and
supplies were also made easier during the ZIKV crisis because of the infrastructure already in place by SUS.

Although SUS is available throughout Brazil, there exist large inequalities and inequity in availability and quality of services provided (Castro, 2016; Castro et, al, 2019; Leal et al, 2018; Souza, Malta, Franca & Barreto, 2018). Throughout Brazil there exist extensive inconsistencies and gaps in SUS access, funding, human resources, organization, resource allocation, and quality, creating regional disparities in healthcare and outcomes (Massuda et.al, 2018). The north and northeast regions - the poorer regions, more rural regions, with less educated persons, and lower socioeconomic classes - are most impacted by these inequities. These regions have fewer doctors per 1000 people than the national average (Gómez, Perez, & Ventura, 2018) as these regions struggle to attract private-sector physicians, specialists, and adequate resources. Within these poorer areas of Brazil, where SUS is often the only option, there exist issues such as scarcity of personnel, lack of equipment, pharmacy stockouts, and long wait periods for special medications and procedures. These factors create regional disparities placing the northeast regions with both the highest burden of disease and greatest unmet healthcare needs (Massuda et. al., 2019). Critics of SUS’ response to ZIKV have stated that the combination of the recession, economic instability, and political turmoil limited the system’s ability to adequately respond to the epidemic and provide adequate care for women and children born with CZS (Castro et, al, 2019; Gómez, Perez, & Ventura, 2018, Leal et al, 2018).
2.2.3. Economic Considerations

During the 2014-2016 economic recession in Brazil, over 1.5 million people lost their jobs and the national poverty rate rose to almost 25% of the population (Massuda, Hone, & Leles, 2018). Crime, homicide, and infectious disease incidence increased while almost 3 million people lost their private insurance, overflowing the already beyond capacity public healthcare system (Massuda, Hone, & Leles, 2018). As a precautionary measure, the Brazilian National Congress carried out budget cuts in healthcare, social programs, research, and education – all of which created a dangerous context for the ZIKV outbreak, as these actions placed vulnerable populations at high risk.

The Brazilian National Congress passed a constitutional amendment in December 2016 to freeze public spending for the next 20 years (Donieca, Dall’Alba, & King, 2018; Ministério de Desenvolvimento Social, 2017). This policy has been a barrier for the allocation of appropriate funds for SUS, research capacity, and medical infrastructure. This financial pause has bound the hands of the scientific community in Brazil, making continued research into ZIKV and other arboviruses more difficult. The Oswaldo Cruz Foundation (Fiocruz)– responded in 2016 during the freezing of funds debates stating: “…the question is: how to ensure control of epidemics such as Zika, dengue, and Chikungunya, including research, assistance, vector control, medicines, and necessary vaccines, with a freeze on resources? The impact on research, fundamental to new products and new solutions that are already underfunded in our country, will incalculable, compromising the long term the capacity for response and national autonomy” (Fiocruz, 2016). Although contested by many public health institutions and researchers, public spending was frozen in 2017 and has remained frozen.
2.3 ZIKV RECOMMENDATIONS AND BEST PRACTICES

2.3.1. World Health Organization

Specific recommendations for the prevention of ZIKV infection vary somewhat across responding organizations. The World Health Organization recommends three main forms of ZIKV prevention: (1) protection from mosquito bites, (2) utilization of condoms to avoid sexual transmission of the disease, and (3) reproductive health counseling with healthcare providers (WHO, 2017b). The World Health Organization states that best practices for protective measures against mosquito transmission are the use of insect repellent, wearing full-coverage clothing, using physical barriers such as screens, cleaning and covering water containers, and removing potential breeding sites (WHO, 2017b). This recommendation assumes that individuals in areas with \textit{Aedes aegypti} have control over the vectors, as well as the intrinsic motivation to engage in vector control behaviors. WHO recommends best practices for reproductive health during the ZIKV epidemic to include “all sexually active men and women be correctly counselled and offered a full range of contraceptive methods to be able to make an informed choice about whether and when to become pregnant to prevent possible adverse pregnancy and fetal outcomes. Women who have had unprotected sex and do not wish to become pregnant due to concerns about Zika virus infection should have ready access to emergency contraceptive services and counselling. Pregnant women should practice safer sex (including correct and consistent use of condoms) or abstain from sexual activity for at least the whole duration of the pregnancy” (WHO, 2017b). These recommendations assume women can access counseling services, obtain contraceptives, successfully negotiate contraceptive use with partners, and decide their reproductive future. Numerous studies have shown that women lack the ability to control their reproductive health in Brazil (Blanchard 2017; Goldthwaite, 2016; Martaleto, 2017;
These recommendations also assume that all healthcare providers have been given adequate training in reproductive and fertility counseling.

2.3.2. The Brazilian Ministry of Health

The Brazilian Ministry of Health has chosen to promote ZIKV prevention almost solely as it relates to vector control. Most health messaging has been centered around mosquito avoidance and vector control such as using repellent. The fertility recommendations made by the Brazilian Ministry of Health advised women to avoid pregnancy during the epidemic until more was known about possible health outcomes, treatments, or vaccines (Ministério da Saúde, 2017a). The Brazilian Ministry of Health also recommends women seek out reproductive health counseling from their healthcare providers. The national Brazilian ZIKV website contains only health messaging centered around vector-based prevention and prevention measures targeted toward women. The website specifically states: “[ZIKV] prevention and control measures are like that of dengue and chikungunya. There are no specific measures of control directed at men, since there is not a vaccine or antiviral drugs” (Ministério da Saúde, 2017b).

The Brazilian Ministry of Health has deviated from the World Health Organization’s ZIKV recommendations by not adequately acknowledging men’s role in the spread of ZIKV nor the sexual transmission of the disease. This lack of adequate messaging can create a greater risk for women to contract the disease. For example, if health messaging fails to discuss the sexual transmission of ZIKV, a man may place their partner, or pregnant partner, at a higher risk for contracting ZIKV through intercourse. Recommendations for ZIKV prevention within Brazil have not been modified since the peak of the epidemic in 2016. The recommendations have been publicized less and have disappeared from media sources since the end of the epidemic was
declared. Healthcare messaging targeted toward pregnancy exists in Brazil but is minute in comparison to that of vector control messaging and prevention methods.

2.3.3. Brazil’s Role in the ZIKV Epidemic

Although it is the opinion that the response taken by the Brazilian Ministry of Health was flawed, placing unjust and unfair burdens on women during the ZIKV epidemic, there are numerous aspects of the Ministry’s response that are commendable. The research that came from Brazil during the early days of the outbreak demonstrated the capacity and strong scientific infrastructure in place throughout Brazil. The scientists, experts, and public health professionals in the Northeast took charge of the situation and were able to demonstrate their abilities to detect, diagnose, and disseminate high level information about ZIKV that aided outbreak responses around the globe.

At the start of the ZIKV epidemic there was little information available to aid health officials, medical personnel, and the public. Research was being conducted simultaneously to response efforts, limiting resources for both lines of effort. It was essential for authorities to be able to continuously reevaluate response efforts and adapt new information and research findings. Brazilian authorities were able to create information, disseminate aid, and facilitate consortiums with global leaders in outbreak response and vector control. Coordination with surveillance teams and reusing of past vector disease response activities allowed for speed in sending public health officials to conduct community-based vector screenings and door to door household observations and education. By utilizing SUS’s extensive network, aid was given to pregnant women and recipients of the conditional cash transfer program, **Bolsa Familia** by delivering free repellent to SUS affiliated public health units while supplies lasted. Authorities’ ability to
quickly respond to the outbreak was essential in mitigating the impact of the ZIKV outbreak, this includes its efforts to create, disseminate, and evaluate health communication focused on preventative behaviors and assistance.

2.3.4. Best Practices in Outbreak Communication

To best understand the gaps in the recommendations provided by Brazilian authorities, it is essential to first understand what best practices in outbreak communication are. The World Health Organization’s best practices in outbreak control includes five components: (1) build trust; (2) announce early; (3) be transparent; (4) respect public concerns; and (5) to plan in advance (WHO, 2005). Brazilian authorities did not have the trust of the community at the start of the outbreak and for a large portion of the crisis. Many rumors and misconceptions about ZIKV and microcephaly flooded the news and social media outlets causing barriers to building trust between the population and health officials. Transparency may have been attempted by Brazilian authorities, but it may not have appeared that way with constantly new findings appearing in the news. Transparency was additionally compromised as it was difficult for authorities to sift through the new information, package, and deliver it to the population as quickly as possible. This lack of initial information, fear, and then rapid influx of information may have presented as unorganized and confusing for the population. To achieve the fourth component of “respecting public concerns”, the authorities would have needed to identify and attempt to address the qualms, barriers, and anxieties of the population. A large cause of concern was if, and how, Brazilian authorities would tackle the social, structural, and economic issues already in place prior to the outbreak, disproportionately effect women and marginalized populations. Additionally, the Brazilian authorities would have needed to address the national
debate which erupted around family planning and reproductive autonomy. The authorities needed to acknowledge these social determinants, tailor messaging to acknowledge these issues, and react in a way that better addressed the feasibility of adhering to the recommendations.

The last component of these best practices includes a component of evaluation and preparation for future outbreaks. Now that ZIKV is a permanent aspect of the Brazilian disease profile - like dengue and chikungunya- future ZIKV management, as well as outbreak management, should be taken into consideration. With a halt in public spending, it is unclear how this plan of action will be strategized and funded. As with all arboviruses, there is a cyclical pattern of outbreak and endemic status, therefore the planning and preparation of this next outbreak is required. ZIKV media and health messaging has stopped all together, instead of acknowledging possible future outbreaks or advising the public for how to prepare for an impending return. The lack of information about ZIKV coming from authorities may create the façade that ZIKV is no longer a problem, therefore suggesting individuals may stop preventative behaviors. This places populations at a higher risk of contracting ZIKV.

2.3.5. Best Practices in Health Communication

Once the public health emergency was declared over, ZIKV did not disappear, but became an endemic disease still present in Brazil. In this transitional period, authorities should have updated their communication strategy and modified it from outbreak communication to a continuous health education communication campaign. There has been a lot of information generated by scientists related to ZIKV and CZS after the epidemic was declared over. New information includes: the definitive studies of sexual transmission of ZIKV, the full spectrum of congenital defects, and evidence of delayed negative birth outcomes. These are discoveries that
were disseminated either toward the end of the epidemic or after the emergency was declared over. ZIKV health messaging was stopped after the epidemic was declared over meaning the public may not have had access to or been exposed to this information. With influxes of other outbreaks such as dengue and chikungunya, health education and information has been returned to solely focusing on the vector and mosquito control, placing reproductive health once again on the back burner.

It is essential to have continuous health education available to the population regarding ZIKV and CZS because there are still areas where transmission is occurring. Information should be diffused throughout communities to ensure people continue ZIKV prevention behaviors. I acknowledge that dengue and chikungunya prevention measures align with some of the ZIKV prevention behaviors, however the family planning, fertility decision-making, and sexual transmission components of ZIKV are not covered in dengue or chikungunya messaging. It should also be acknowledged that the typical vector control messaging is flawed as it has been recycled without proper tailoring for decades.

2.4. CHALLENGES TO ADHERING TO RECOMMENDATIONS

The Brazilian Ministry of Health has publicized two main recommendations pertaining to ZIKV: (1) vector-based prevention and (2) pregnancy avoidance or seeking out reproductive health counseling. These recommendations assume people have the power to adhere to these sanctions, utilizing the best practices previously mentioned by the World Health Organization. These directives were generic recommendations disseminated nationally, that ignored the unique conditions of the most vulnerable populations constrained by social determinants within the
context of Brazil. A plethora of contextual issues are not being considered in the Ministry of Health’s response to the epidemic. By not considering these contextual factors and societal constraints, it is assumed all Brazilians have equal ability and power to protect themselves from ZIKV and its potential health outcomes. This dissertation explores women’s ability to adhere to the pregnancy/reproductive health recommendation put forth by the Brazilian Ministry of Health, while taking into consideration the social determinants of income, class, and gender.

2.4.1. Recommendation 1: Vector-based Prevention

Due to the high prevalence of mosquito-based transmission of ZIKV, and the enormous amount of programming and funding it has received from the Brazilian Ministry of Health, it is essential to acknowledge this recommendation. Vector control has a history of ineffectiveness within Brazil as well as the rest of Latin America (Weaver, 2016). While elimination was achieved in Brazil in the 1940’s and 1950’s, the mosquito was soon thereafter reintroduced with its potential for disease transmission (Leontsini, Gil, Kendall, & Clark, 1993; Winch, Kendall, & Gubler, 1992; Winch, Lloyd, Hoemeke, & Leontsinia, 1994).

Brazil has long been fighting vectors and its associated diseases of dengue, chikungunya, yellow fever, malaria, and now ZIKV. In its earliest times of the sixteenth century, health efforts in Brazil were focused on malaria control. In the twentieth century malaria continued to be a major health risk with the rise of deforestation and industrialization (Griffing, Tauil, Udhayakumar, & Silva-Flannery, 2015). Throughout this century Brazil was at the forefront of malaria and yellow fever research and control – the first to use DDT systematically while maintaining surveillance of cases nationally (Araújo et. al, 2015; Leontsini, Gil, Kendall, & Clark, 1993; Winch, Kendall, & Gubler, 1992; Winch, Lloyd, Hoemeke, & Leontsinia, 1994).
As research, control, prevention, and surveillance efforts strengthened, Brazil’s malaria and yellow fever incidence dropped and outbreaks of other diseases such as dengue and chikungunya began to appear in the latter half of the twentieth century. A multi-national effort was established throughout Latin America, and eradication of the vector was declared in the 1950’s (Araújo et al., 2015; Kotsakiozi et al., 2017).

Due to discontinued funding, lessened efforts, poor coordination, and reintroduction of the mosquito, the diseases returned, and Brazil has experienced cycles of yellow fever, malaria, dengue, and chikungunya outbreaks throughout the last 50 years (Leontsini, 1993; Winch, 1994). Throughout that time Brazil’s responses to the outbreaks have been redundant with the use of chemical sprays, larvicides, home observations, and basic educational campaigns. Although redundant, the surveillance and core activities of Brazil’s responses have been partially efficacious with morbidity and mortality rates steadily decreasing (Kotsakiozi et al., 2017). The system in place has yet to control the mosquito or bolster its preventative efforts to reduce the number of outbreaks occurring annually. This antiquated approach was duplicated in ZIKV response efforts. Although this replication was not ideal, it did allow response efforts to be quickly rolled out due to the familiarity of the vector. Had the vector control infrastructure not been in place, perhaps the ZIKV epidemic would have been worse.

The Brazilian Ministry of Health has been attempting to improve their national vector control efforts, as a response to ZIKV, since 2015. According to the official Brazilian Ministry of Health Report ZIKV in Brazil: The SUS Response, the mobilization plan for the Zika epidemic involved the creation of the “National Plan to Combat the Aedes and its Consequences”. This plan is an inter-ministerial effort to do address three goals: (1) mobilization and combat against mosquitos, (2) health care and assistance to people; and (3) technological development,
education, and research. The government further created Municipal Coordination and Control Offices (SMCC) to be stationed throughout Brazil. Each office works to oversee \textit{Aedes aegypti} control campaigns and ZIKV educational campaigns. These offices are also responsible for monitoring the incidence and prevalence of ZIKV. Although the north and northeast regions of Brazil comprise more cases of ZIKV, these areas were given fewer municipal offices to aid in their ZIKV prevention efforts. The report states the following number of SMCC offices per region: North Region (106 SMCCs), Northeast Region (237 SMCCs), Southeast Region (721 SMCCs), South Region (476 SMCCs), and the Midwest Region (256 SMCC) (Ministério da Saúde, 2017a). These offices have since been defunded, deserted, and dismantled.

Vector control is challenging as it cannot be effective if control measures are not adhered to with rigor and continuity. Vector control is additionally impacted by DDT resistance, a lack of political will to invest money, a sustained flow of resources, and a lack of consistently cohesive national programming. The \textit{Aedes aegypti} cannot be fully contained if there is a lack of community level efforts targeted toward vector control. If one's neighbors are not adhering to control measures, the impact of vector control efforts is lessened, placing all individuals in the community at a higher risk of contracting a vector-borne disease. A lack of complete community involvement may deter individuals from attending to mosquito control measures within their home if they believe their effort would be impractical in lieu of their neighbor's unwillingness to complete the behavior as well.

Vector control is also needed in typically the poorest and most neglected areas. These populations often live in areas with inadequate domestic and environmental infrastructure. It is common for water delivery and waste management services to not be regularly accessible in these areas (Braga, 2017). This may create a need amongst residents to store water, creating a
potential breeding ground for the mosquitos. Individuals storing the water may be unwilling to
dump or remove their stored water due to the necessity and scarcity of the resource. Low income
populations may also live along streets or streams where water and garbage accumulate, or
where fumigation trucks cannot, or will not, enter. These individuals may not be able to afford
screens on windows or personal repellent (Azeredo, 2018; Braga, 2017; Christofferson, 2016).
Screens on windows is an anomaly in Brazil. Without standardized sizes for homes and windows
throughout Brazil, there is no justification for the manufacturing of window screens. Similar
sized homes with mass-produced infrastructure is a modern, Western architectural component,
not present in Brazil, therefore screens are hard to find and are often needed to be customized to
the specifics of a person’s home.

These vector control behaviors may also be rejected due to the tediousness of the
preventative measure or fear of insecticides. For example, the time and attention it would take to
properly clean water storage containers may be perceived as bothersome. Recommendations for
repeated applications of repellent, or full coverage clothing, are not usually utilized when
individuals are in their home. Utilizing thick, long clothes in the very hot and humid regions of
Brazil is not likely to be adhered to. The redundancy of vector control approaches and normalcy
of living with the vector may additionally lead to complacency. With high levels of incidence
and a long history of cohabitation with the mosquito, some individuals may fall complacent or
passive in their situation. A high level of consistent incidence of arboviruses in the community,
without negative health outcomes, could lead people to have a lower risk perception, thus
lowering their intrinsic motivation to comply to prevention measures. Alternatively, if a person is
correctly adhering to the mosquito control protocols, yet contracts an arbovirus, that person may
feel they have no control over the vector and may stop all mosquito mitigating behaviors.
As of now, the Brazilian Ministry of Health’s offense against ZIKV is primarily vector control, with almost all country-level health messaging and national funds being placed in vector education, control, and awareness. The Brazilian government allocated copious financial investments in vector control within Brazil (Alfaro-Murillo et al., 2016) – yet these efforts have consistently failed since the 1960’s to interrupt the epidemic transmission of arboviral infections. It is not be the primary purpose of this dissertation to evaluate the Aedes aegypti control program, but other elements of the ZIKV response such as family planning and reproductive health.

2.4.2. Recommendation 2: Pregnancy avoidance and reproductive health counseling

Women were being advised to postpone pregnant during the Zika epidemic. This advice ignores Brazil’s high unintended pregnancy rate and furthermore assumes women have control over conceiving a child (Schuck-Paim, López, Simonsen, & Alonso, 2016). Data from the extensive “Birth in Brazil National Survey” (2012) indicated that 55% of all births were unintended (Le, 2014). This speaks to issues of unmet contraceptive need and a possible inability to advocate and adhere to a preferred fertility decision. Most Brazilian women who are at risk for unplanned pregnancies live in areas with a high prevalence of the ZIKV (Baum, 2016; Diniz, D., 2016b; Diniz, S., 2016). In June 2016, a national survey was disseminated throughout Brazil exploring women’s decision to avoid pregnancy during the ZIKV epidemic. Approximately 54% of women reported they had avoided pregnancy due to the ZIKV epidemic (Diniz, Medeiros, & Madeiro, 2017a). This survey furthermore identified that 66% of women from the Northeastern region of Brazil reported wanting to avoid pregnancy due to ZIKV but felt they did not have total control over that decision (Diniz, Medeiros, & Madeiro, 2017a). With high levels of women
seeking to avoid pregnancy, there needs to be comprehensive family planning options to meet that need (Blanchard 2017; Rasanathan, 2017; Schuck-Paim, López, Simonsen, & Alonso, 2016).

It was the World Health Organization who stated that best practices for ZIKV prevention would entail all sexually active individuals be provided with reproductive health counselling and options for a full range of contraceptive methods in order to be able to make an informed choice about if, and when, to become pregnant (WHO, 2017b). Reports have shown that counseling services have not been provided to pregnant women or women contemplating pregnancy in Brazil (Wurth, 2017). Unintended pregnancy rates often suggest an unmet need for family planning resources, but it should be added that the unintended pregnancy rate could suggest a social pressure to conceive or avoid use of those resources.

2.4.3. Contraceptive Utilization

Simply introducing an influx of contraceptives into Brazil will not solve the issue of women adhering to an informed fertility decision of their choice. Under-resourced public health units, difficulty in affording and accessing transportation to health clinics, limited access to reproductive health information, lack of full range of contraceptive services, lack of adequately trained healthcare personnel, and unequal power dynamics within intimate relationships create barriers for women to access and use contraceptive information and methods (Baum, 2016; Burke & Moreau, 2016; Galli & Deslandes, 2016; Velez, 2016). These barriers are further exacerbated when a woman is of low socioeconomic position, low class, or lives in a resource-poor area of the country. Frequently these women are dependent on the income of their partner to support her and possibly her family. Women often do not have the power to abstain from
intercourse, or advocate for condom use during intercourse due to these contextual factors (Baum, 2016; Guanilo et al., 2014; Rao, 2016). A 2008 Brazilian study found that 21% of males reported consistent condom use, while only 14.4% of women reported consistent condom use (Paiva et al., 2008). These numbers are expected to be higher than the actual utilization rates, due to self-reporting bias. Numerous studies have documented women reporting an inability to advocate for their partner to use a condom (Diniz, 2016; Duarte, 2016; Le, 2014; Paiva, 2008, Robinson et al., 2017). Reasons for this include fear of negative perceptions for requesting the use of a condom, fear of physical abuse, fear of the partner leaving them, or fear of their partner withholding of finances (Diniz, 2016; Duarte, 2016; Le, 2014; Paiva, 2008, Robinson et al., 2017). Qualitative reports documenting women’s contraceptive use during the ZIKV epidemic, reported women acknowledging an inability to utilize condoms during intercourse despite the threat of ZIKV (Burke 2016; Martaleto, 2017; Borges 2018). Women (both pregnant and non-pregnant) stated that although they wanted to use protection, their partner was unwilling to use a condom. A male partner’s unwillingness to use a condom was found to be the most frequently reported cause for a couple to not use protection (Burke 2016; Martaleto, 2017; Borges 2018).

2.4.4. Policy Considerations (Abortion and Health Insurance)

A woman’s income dictates her ability to purchase private sector services, which furthermore dictates her ability to receive a full range of contraceptive options and possibly needed abortion services. Abortion in Brazil is illegal unless under one of the following situations: (1) if the woman was raped; (2) if the woman’s life is in danger; or (3) if the child is at risk for anencephaly (Borges, 2017). Women who seek care related to abortion services are often treated with institutional discrimination and violence within the healthcare setting (Colluci,
Abortion although illegal can be found within the private sector for women who have the financial means to purchase these services. Unsafe abortion such as a self-induced abortion using misoprostol or herbs is commonly found within poorer communities of women, where an expensive private sector abortion is not available (Diniz et al., 2017).

Unsafe abortion is a public health problem in Brazil, with distinct regional differences, mainly placing more burden and less access on the socioeconomically disadvantaged regions of the country – the north and northeastern regions (Castiglione, 2018; Harris, Silvermann, & Marshall, 2016). Outcomes associated with unsafe abortions make up a quarter of a million-emergency room visits each year (Diniz, 2017; Roa, 2016). This figure is likely to be lower than the actual number since a woman admitting to inducing an abortion is a criminal offense. Both the woman and the physician who helps her with associated complications could be charged. Unsafe abortions have continuously been one of the leading five cause of maternal mortality within Brazil for over a century (Colluci, 2016; Roa, 2016; Tambo, 2017).

Due to the illegality of the service and issues with self-reporting bias, the exact scope of unsafe abortions are unknown but are estimated at an annual rate of about 750,00 to 1.25 million unsafe abortions performed annually in Brazil (Diniz, Medeiros, Madeiro, 2017b). The north and northeast regions of Brazil encompass the highest unsafe abortion rates in the nation. Unsafe abortion was found to be one of the main causes of maternal death in several capitals of these regions (Ali, 2017). These are the same areas being disproportionately impacted by ZIKV. After the PAHO alert regarding the initial ZIKV outbreak, Brazil saw a 108% rise in online requests for illegal abortion medications (mifepristone and misoprostol) from online nonprofit suppliers (Aiken, 2016). Inequity and inequality exist among women’s options in contraceptives, emergency contraceptives, and abortion services. Those in the private sector can utilize the full
range of contraceptives recommended by the World Health Organization for ZIKV prevention, while public healthcare users are subject to inconsistencies in these services. For women who utilize the public health sector of Brazil, these inconsistencies act as barriers to their ability to adhere to the Ministry of Health’s ZIKV prevention recommendation to avoid pregnancy during the ZIKV epidemic.

2.4.5. Reproductive and Fertility Decision-Making

Nationally, the fertility rate in Brazil has been on the decline for the last several decades suggesting an increase in available family planning services and education. Estimates from the *Instituto Brasileiro de Geografia e Estatística (IBGE)* state the Brazilian fertility rate decreased from 2.14 children per woman in 2004 to 1.74 in 2014 (Instituto Brasileiro de Geografia e Estatística, 2015). Although the national fertility rate has been declining, the north and northeast regions of Brazil still have significantly higher fertility rates than elsewhere in the country (Martins-Melo, 2014). Cultural factors such as familial pressure to have a large family could be impacting these higher fertility rates. It is also possible that there is an inability to control one’s fertility as well as a lack of needed public health services.

A lack of ability to fully utilize the public sector, as well as patient-provider communication issues, could lead to women being unable or unwilling to receive fertility or reproductive health counselling. National SUS surveys have shown that most women do not receive reproductive health counselling in their public-sector health visits, and over 71% of women report low levels of satisfaction with the interactions they experienced during their last health visit (Malta, 2010; Castiglione, 2018). This is an even greater issue in the Northeast where over 76% of individuals only have access to the public health sector (Carvalho, 2017). This area
of Brazil is also associated with higher levels of obstetric complications. A study by Rosendo found that these higher levels of obstetric complications were associated with non-white race, lower socioeconomic position, care received in a public facility, a lack of counseling during pregnancy, and use of public services (2017). Women need precise information about contraceptive options and access to services that respect women’s choices about contraception and conception. Individuals and couples considering pregnancy need up-to-date and accurate information about the risks and potential effects of ZIKV infection, and advice about timing a pregnancy. For women in ZIKV effected areas, counselling on their fertility decision and reproductive health is crucial.

2.4.6. Cultural Considerations: Traditional Gender Roles

Academics in anthropology, sociology, and public health have noted strong traditional gender role adherence in Brazil, especially in Northeastern Brazil (Dalsgaard, 2012; DeSouza & Baldwin, 2000; Neuhouser, 2008; Rebhun, 1991; Schep-Hughes, 1992). These traditional gender roles typically represent the religious, polarized ideas of modelo de Maria and machismo - or marianismo and machismo (Neuhouser, 2008). The ideas of the modelo da Maria perpetuate the persona of the Virgin Mary as the female ideal. Strong religious and traditional acceptance and worship of the Virgin Mary has created a normalization of piety, purity, self-sacrifice, motherhood, and submission as feminine values throughout Latin America, especially in Brazil. Machismo often describes a hypermasculinity of dominating and aggressive behaviors (DeSouza & Baldwin, 2000; Neuhouser, 1989; Neuhouser, 2008). These two identities are viewed as opposite values for the sexes yet are interrelated to create a balance in the household. These religious sects often advocate for these gender roles and admonish women and young girls for
promiscuity, sexuality, pregnancy out of wedlock, or lack of desire to reproduce (Steele, 2011). These conservative ideologies are re-gaining popularity and power due to recent changes in political parties and ideologies (Câmara, Sentell, Bassani, Domingues & Pirkle, 2019). Such conservative ideologies can impact perceptions toward contraceptives and abortion, access to family planning, and inclusion of comprehensive sex education in schools.

These gender roles are often reflected in gender power dynamics and sexual relations where men are perceived as “in-control” and “active”, while women and female sexuality is expected to be “passive” and subject to male desire (DeSouza & Baldwin, 2000). These gender roles do not act alone, they are often impacted by social determinants such as age, race, and class. As will be discussed through the lens of the Theory of Gender and Power, these power dynamics can impact household behaviors, household spending, contraceptive usage, and women’s perceived self-efficacy. Rejection of these gender roles can also impact a woman’s reputation or social standing. Work by Rebhun suggests sexual reputation is an important factor in a woman’s social standing in Brazil, and even more so in the Northeast (2008).

According to the aforementioned Brazilian scholars, expression of sexuality comes with social consequences which may be exacerbated by a woman’s race, class, income level, and location of residence. Sexuality, pregnancy, and stigma are highly intertwined with morality in the Northeast which may create barriers to safe sex practices, accessing contraceptives, and prenatal healthcare seeking. When thinking about ZIKV specifically -and its relation to sexual transmission of disease, family planning usage, and reproductive autonomy - these deep-rooted and core aspects of Brazilian identity and gender roles cannot be ignored.
2.4.7. *Motherhood*

Gender identities, religious affiliations, region of origin, age, race, and social class can all impact women’s perceptions of womanhood and motherhood. For men, fatherhood is often viewed as optional because of men’s ability to leave the woman or have children with multiple women without much social stigma. For men, having numerous children is a sign of fertility and a sign of masculinity or “maleness” (Neuhouser, 2008). This can lead to men pressuring women to become pregnant, not using condoms, or forbidding the use of contraceptives. Brazil as a nation has shown strong acceptance toward traditional roles of motherhood. The latest International Social Survey Programme (ISSP) demonstrated that out of approximately 40 countries represented, Brazil had the highest acceptance of motherhood – for example Brazil reported the highest percentage of respondents (91%) who believed rearing children was “life’s greatest joy” and the highest level of respondents (78%) who believed people without children “lead empty lives” (ISSP, 2012). It should be noted that a higher acceptance of these ideas was inversely related to income and education.

Although there is strong support for motherhood in Brazil, this acceptance does come with some exceptions. For example, as previously discussed pregnancy out of wedlock is often considered immoral and stigmatized by religious individuals and organizations. Having too many children is also stigmatized, especially for the poor. For many women being a mother means being the sole or primary caregiver of the child(ren), meaning it is her responsibility to feed, dress, educate, and care for their health. These responsibilities and ability to procreate are often tied to the woman’s economic status – meaning the more affluent she is the easier it is to best fully care for her children. Therefore, for lower income women, having numerous children is often seen as irresponsible because it suggests the children would not be able to be cared for
adequately (Dalsgaard, 2004). For lower class or lower income women, multiple pregnancies are often viewed as poor planning and met with stigma by both people within the same economic group, as well as wealthier individuals.

Motherhood is frequently associated with women keeping a home (cleaning the house, cooking, caring for the children, etc.) while men venture outside the home to find work and income to provide for the family. The woman’s gendered role typically assumes responsibility of the home and children, therefore strongly associated with the hygiene, cleanliness of the house, and wellness of the children. The state of the home and children is believed to be a good measure of a woman’s ability to fulfill her role.

Motherhood is an identity intertwined with femininity and womanhood. For many young girls and women (especially those of low socioeconomic status and low education) “mother” is the only positive female identity that exists for them. Motherhood is frequently associated with a good woman, a caring person, a submissive wife, a faithful worshipper of God, a compliant patient, and a responsible citizen (Dalsgaard, 2004; Neuhouser, 1998; Schep-er-Hughes, 1992). For many in Brazil, womanhood is not separate from motherhood, but is the completion of motherhood. In order to prevent pregnancy, women are trapped in a “double bind” as motherhood is often dependent upon the man who holds most, if not all, of the power and control within the relationship. To adhere to gender norms, the woman must be passive in her relationship, but to prevent pregnancy she must break that gender norm and take initiative to take control over her body. Ethnographies focused on motherhood in Brazil has demonstrated the spectrum of perceptions toward motherhood – fulfillment, joy, difficult, responsibility, respectability, wholesome, a criterion, an obligation, an aspiration, a way of recognition, and a sacrifice (Dalsgaard, 2004; Neuhouser, 1998; Schep-er-Hughes, 1992). This dissertation will add
to that body of ethnography to help identify how women in Fortaleza, Brazil conceptualize fertility and motherhood as it relates to ZIKV.

2.5. THEORETICAL CONSIDERATIONS AND CONCEPTUAL FRAMEWORK

A lack of social science theory limited the relevance and efficacy of health recommendations made during the ZIKV epidemic. Had those who created the ZIKV recommendations utilized theory in explaining the context or the development of successful behavior change strategies, the recommendations may have been more appropriately tailored to the population of interest. The most controversial recommendation was for women to avoid becoming pregnant during the epidemic. This recommendation assumes women have control over this decision and regularly plan pregnancies, yet the reality of the situation in Brazil is that an imbalanced power dynamic between partners can create male-centered fertility decision-making, forcing women to sublimate her desired fertility decisions—which is often to abstain from becoming pregnant (Blanc, 2018; Meireles, 2017; Galli, 2016).

This dissertation borrows from the Theory of Gender and Power as this theory’s central concept is that inequalities and inequities in gender, income, and class are the root causes of structural and cultural mechanisms which create obstacles for women to pursue desires such as preferred fertility decisions. This dissertation echoes sentiments from feminist writers and theorists that conceptualize female reproduction, while a biological phenomenon, as an event which is culturally charged and socially constructed (Colen, 1995; Ginsburg & Rapp, 1995; Inhorn & van Balen, 2002). By not acknowledging the non-biological components of reproduction, women’s autonomy in reproductive and fertility decision-making is being
overestimated by the Brazilian authorities, therefore placing women disproportionately at risk for negative health outcomes associated with ZIKV.

2.5.1. Theory of Gender and Power

The Theory of Gender and Power is relevant given its approach to the intersectionality of gender, income, and societal imbalances among the sexes. This dissertation is interested in how this intersectionality places women in a less effective position to negotiate sexual and reproductive health decisions. The Theory of Gender and Power is based on three pillars: the sexual division of labor, the structure of cathexis, and the sexual division of power (Connell, 1987; Wingood & DiClemente, 2000). These three concepts although presented separately, do overlap, as each work to influence the components of the other. Wingood and DiClemente (2000) states:

“The three social structures are maintained within institutions through social mechanisms such as unequal pay for comparable work, discriminatory practices at school and work, the imbalance of control within relationships and at work sites, and the stereotypical and/or degrading images of women in the media. The presence of these and other social mechanisms constrains women’s daily lifestyle practices by producing gender-based inequities in women’s economic potential, women’s control of resources, and gender-based expectations of women’s role in society” (p.543)

The sexual division of labor speaks to the issues of gendered opportunities for work, education, and income which disproportionately favor men, giving them more control over household power, income, and resources. Women are often working in unequal positions relative to men, which are reinforced by social and cultural norms. For example, women may need to stop their
education to tend to the home, while men may leave the home to obtain higher education or to seek out employment. Women may be caring for children, attending to housework, and cooking for the family – but it is often the man who earns monetary income which allows him to dictate how that money can be used. This creates an economic imbalance causing women to rely on men financially. This can impact a woman’s self-efficacy and autonomy within the household. This financial gap can also be created through gendered pay differences even if both individuals are employed. For example, according to the 2018 national survey from the Brazilian Instituto Brasileiro de Geografia e Estatística (IBGE) women on average earn 20.5% fewer wages than men (IBGE, 2019). Women in the workplace additionally experience high levels of hiring and work-related discrimination and harassment.

The sexualized division of power is the most salient arm of this theory, and one that is echoed throughout this dissertation. The definition of power I use in this dissertation is the one best represented by the Theory of Gender and Power. Theorists acknowledge two main conceptualizations of power: power over others and power over oneself – this theory and I recognize power to be both power over others and power over oneself (Connell, 1987). This theory posits that a loss of power or lack of exercising power could be due to religious affiliations, traditional cultural norms, a lack of financial access, or a general lack of control within the household or situation. I hypothesize that it is these structural, cultural, and power imbalances among men and women can place women in a position to be either unable to exercise their fertility decision-making power or be too afraid to explore her ability to exercise her wishes.

The structure of cathexis works at the societal, institutional, community, interpersonal, and individual level to create and enforce social norms that dictate what is appropriate sexual
behavior for women. This rhetoric of approved sexual practices sets expectations for how a woman should act in her relationships with men and molds how women are viewed. This structure of cathexis is often modified or amplified by media’s portrayals of women which often reinforce stereotypes or influence women’s behavior. This structure can be applied to the ZIKV epidemic when thinking about the reproductive rights of women, women’s abilities to advocate for safer sexual practices, or the use of family planning. This is also relevant to how individuals may view women who are pregnant out of wedlock, who are pregnant at a young age, or who engage in sexual activities without the intent to become pregnant. The structure of cathexis and structure of power interconnect when thinking about how women may negotiate condom use with their partner as both a contraceptive and a prevention method for ZIKV.

Women’s ability to adhere to fertility desires is constrained by both gender dynamics and power dynamics supported and perpetuated through income inequities. It is essential to acknowledge that while gender is relevant to understanding this issue, it is also essential to understand how income can mitigate the constraint of gender on these women’s autonomy in fertility decision-making. Men often dictate fertility decisions due to their stronger ability to negotiate behavior the power they hold by receiving higher wages and controlling household expenditures (Holerbach, 1980; Klawon, 2001). Power differentials in sexual relationships directly influence women’s access to and use of reproductive health services when male partners control financial resources and women’s mobility. This then places women at a higher risk for an unwanted pregnancy and STDs (in this case ZIKV) because they have less ability to negotiate protection from the disease or from becoming pregnant (Blanc, 2018; Galli, 2016; Goldthwaite, 2016). Conversely, a more affluent woman may be less dependent on her partner, have private health insurance increasing her access to contraceptives and pregnancy termination services, and
may have the physical means (repellent, long clothing, adequate housing) to improve her ability to prevent ZIKV. The social underbelly of the ZIKV epidemic cannot be neglected, because it is in this social labyrinth that gender-based inequities and disparities are produced such as women’s access to resources, household autonomy, educational capabilities, wage discrepancies, and gender-based expectations of their role in society. These inequities and disparities can manifest as risk factors that increase women’s vulnerability to ZIKV and its associated health outcomes.

2.5.2. Stratified Reproduction

A second lens used in this dissertation is stratified reproduction, which stems from Connell’s work of the Theory of Gender and Power. Stratified reproduction is a concept from Shellee Colen that emerged during the feminist movement of the latter half of the twentieth century. This idea states that there are imbalances in the ability of people of different races, ethnicities, classes, and genders to reproduce and nurture their children – some are empowered to reproduce, others are disempowered; some can exercise their reproductive rights, others are unable to exercise those rights (Colen, 1995; Ginsburg & Rapp, 1995). Colen argues women are held to different reproductive standards according to their income, class, and ethnicity. This lens furthermore acknowledges that women often do not have a choice in their fertility decision-making process or reproductive lives, as societal standards, social expectations, and monetary ability dictate the level of power women have in becoming pregnant and rearing children. Stratified reproduction moreover acknowledges that a society’s normalization of motherhood and determination of what femininity “should be”, can remove women’s power within the fertility decision-making process (Colen, 1995; Ginsburg & Rapp, 1995; Inhorn & van Balen, 2002).
Stratified reproduction compliments the Theory of Gender and Power as it acknowledges that women often lack power within the household which impedes their ability to make decisions about sexual behavior and family planning (Connell, 1987; Ginsburg & Rapp, 1995). There is an overlap in these theories as they demonstrate that power of reproductive or fertility choices are often associated with an overestimation of the amount of agency women have within their lives and within their relationships. This agency is assumed in the ZIKV recommendations which neglect the challenges facing women’s reproductive autonomy and the feasibility of adhering to these recommendations. These sanctions also assume that the reproductive lives of women throughout Brazil are homogenous – stratified reproduction allows a lens that acknowledges women experience reproduction and fertility differently, experiences of fertility that are guided by political, systemic, structural, and social influences.

Stratified reproduction extends to the decisions, outcomes, and behaviors of a woman’s entire reproductive life – therefore this lens is applied to both the aspect of fertility decision-making, as well as the abilities and ways in which mothers care for their children and perceive “motherhood”. More specifically, I apply stratified reproduction to the interviews and case studies collected of mothers of children with Congenital Zika Syndrome, pregnant women, and mothers who recently had children. This allows these experiences to be viewed as individualistic while allowing for an understanding of the institutional and societal level components influencing the decisions, options, and behaviors of the women interviewed.
2.5.3. Conceptual Model of Fertility Decision-Making as a Response to The ZIKV Epidemic

This model, based on the work of Crankshaw (2012), identifies the key mechanisms of couples’ dynamic of fertility decision-making within the context of the ZIKV epidemic. The individual determinants identify the components that both partners bring to the relationship in terms of knowledge, attitudes, and exposure to ZIKV. These components, as well as the structural domain (societal factors in grey), further influence gendered power within the relationship.
The conceptual model emphasizes gender power and communication as being the key components in choosing a behavioral outcome. These mechanisms can influence each other as well as the decision-making process. The model continues to illustrate the three general risk reduction behaviors the couple may take and the subsequent outcome of each behavior. This model is based off a conceptual framework for understanding HIV risk behavior in the context of supporting fertility goals among HIV-serodiscordant couples (Crankshaw, 2012).

Past studies related to HIV-serodiscordant couples in Brazil found similar power dynamic issues and determinants within reproductive health and fertility decision-making (Guanilo, 2014; Paiva 2007; Robinson 2017). It is important to note that studies related to HIV-serodiscordant couples in Brazil found that fear of negative perceptions from healthcare providers was a common factor in the fertility decision-making among women, but not men. A similarity can be drawn between the climate of HIV-serodiscordant couples and ZIKV positive couples today. Fear of stigma and admonishment from healthcare providers may be a point of anxiety among women wishing to seek out counseling during the ZIKV epidemic.

It would not be appropriate to have a conceptual model that solely focuses on the individual or interpersonal level components because that would suggest these behaviors could be made autonomously without considering the complexities of external factors often non-modifiable by the woman or couple. The Theory of Gender and Power has often been utilized in research because it steps away from an individualistic conceptualization and considers the breadth of the context of women’s lives. By merging concepts of Theory of Gender and Power, as well as Crankshaw’s model, I created a conceptual model that seeks to acknowledge the decision-making process does not exist within a vacuum but is influenced by contextual factors
such as gender roles and power structures which may increase women’s likelihood of experiencing negative ZIKV related health outcomes.

The construct of “External Factors” encompasses the societal, community, interpersonal, and individual level factors which may impact this decision-making framework. Societal factors such as sociopolitical environment, vector control programs, cultural norms, and national family planning policies may impact the individual’s access and perceived availability of ZIKV prevention resources. Factors such as negative interactions with healthcare providers, type of health insurance, ZIKV-associated stigma, and income of the individual may impact the health seeking behaviors of the individuals. Income and educational attainment could impact ZIKV knowledge, the power balances within this relationship, condom negotiation, water storage practices, and cleanliness of the home which could all act as factors for exposure to ZIKV.

This conceptual model acknowledges the fertility decision-making process as one heavily impacted by individual factors, interpersonal dynamics, as well as a plethora of external influences. Qualitative, ethnographic work captured the components of interest described in this model while additionally delving deeper into the interconnectedness of these factors and paths in which these influencers effect women’s fertility decision-making.

2.6. STUDY SETTING

Brazil is at the epicenter of the ZIKV epidemic, with approximately 60% of globally reported cases within its borders (PAHO, 2018). Fortaleza is a city found in Northeast Brazil, in the state of Ceará. This state has experienced significant amounts of exposure to ZIKV with 3,495 suspected cases of ZIKV reported in 2017 (Secretaria da Saúde do Estado do Ceará, 2019). In 2018, there has been a decline in suspected cases of ZIKV in Ceará (n=590), although
distribution of the cases has spread to 41.3% of the municipalities (Secretaria da Saúde do Estado do Ceará, 2018). Approximately 65.9% of those reported ZIKV cases were in the 20- and 39-years age range – a concern for women of reproductive age (Secretaria da Saúde do Estado do Ceará, 2018). It should be noted that these reported cases do not represent the true extent of ZIKV cases in Ceará since about 80% of cases are asymptomatic. An asymptomatic patient would not seek healthcare therefore their case could not be reported for the national registry.

Fortaleza, Ceará is a tourist destination for both Brazilians and outsiders. Along its beautiful beaches you will find expensive hotels, restaurants, and infrastructure created for the affluent and wealthy. This tourist hub is of importance as it allows for Fortaleza to be exposed to traveling populations who may transmit ZIKV, likewise the high incidence of ZIKV within Fortaleza is a concern for those tourists who visit. Just behind the beautiful façade are the areas of the middle class and favelas. The state of Ceará, and the Northeast region of the country is comprised mostly of individuals who fall under the category D and E in the Brazilian social class socioeconomic ranking system (Associação Brasileira de Empresas de Pesquisa, 2016). This social class system is calculated utilizing individuals’ ownership of household appliances, occupation, years of education, monthly income, and access to utilities. A classification of D/E suggests most individuals within this group solely utilize the public health sector, have an income less than $3.152 reais a month ($0.83 dollars), are mostly minimum wage earners or unemployed, and have not finished high school (Associação Brasileira de Empresas de Pesquisa, 2016). For further explanation of the social class structure in Brazil, please see Figure 3. Socioeconomic Class in Brazil.

Primary Health Units (PHUs) are the first level of contact in the SUS system. Fortaleza’s government and public health institutes have a long history of supporting and fostering the PHUs
so they may be an efficacious first line of prevention, education, and treatment for much of the population who solely utilize the public health insurance and provisions through SUS and Bolsa Família. There are 96 PHUs in Fortaleza divided into six health regions and a downtown business district. PHUs are healthcare facilities staffed by six or more physicians, nurses, nurse assistants, community health agents, pharmacists, and a dentist. Twelve PHUs are designated for Medical Residency and medical student training and are the best equipped and staffed. Three of these 12 sites have been selected from regions suspected of the largest number of vector-borne disease cases and are currently under the direct supervision of the Federal University of Ceará, which is the partner in this study. Two of those PHUs were used in this dissertation for data collection purposes. At the time of data collection there was a gang-related wave of violence throughout the city, therefore the third PHU was closed for safety reasons. The high level of violence at the time may have deterred women from visiting the PHU and may have skewed possible participation in data collection. The wave of violence also created a risk to me and the research team which was a factor in determining the shorter than preferred timeline of the study.

2.6.1. ZIF Study

This study was nested in a larger cohort study “Zika em Fortaleza: respostas de uma coorte de mulheres entre 15 e 39 anos (ZIF)” (“Zika in Fortaleza: Response of a cohort of women aged 15-39”). The cohort study is led by a research team based in Fortaleza and directed by principle investigator, Dr. Ligia Kerr, MD, MPH, PhD. and co-PI Dr. Carl Kendall, MA, PhD. The primary investigator of this study is Dr. Ligia Kerr, Senior Professor of Epidemiology, Department of Community Health, Federal University of Ceará. Dr. Carl Kendall serves as Co-Director of this CNPq funded project. Since the writing of the R01 proposal, I have been a part
of the research team and have assisted with the study. The research team includes epidemiologists, biostatisticians, medical doctors, nurses, anthropologists, lab technicians, and doctoral students at the Federal University of Ceará. The cohort study began recruitment in 2016 and followed 1472 women recruited in three public clinics in Fortaleza.

ZIF includes a qualitative and a survey quantitative component: the qualitative assessment uses a rapid assessment approach in a sub-sample of women recruited to the cohort survey component. Women recruited to the survey undergo a series of lab tests: ZIKV, dengue, and chikungunya (IgG and IgM) that are repeated at each round. The cohort includes women between 15 and 39 years old, living in Fortaleza, who utilize the public health sector, who have been sexually active within the last year, and who are at risk of pregnancy (i.e. have not received a tubal ligation). The specific aims of ZIF are:

- To calculate the prevalence and incidence of ZIKV infection among the women followed by the cohort and the associated risk factors;
- To measure the knowledge and interpretation of the recommendation promoted in the media and received by health professionals by the studied population on: Zika, Zika transmission, consequences of conception, pregnancy in the context of the Zika epidemic, the mosquito and how to avoid contact; family planning for Zika infection, and abortion;
- To measure the intentions of getting pregnant and the pregnancies that occurred in the context of the infection, and seeking health services in the different moments related to Zika (in the case of fever, questions regarding Zika, if pregnant, desire for family planning, desire for abortion, etc.)

The study has recruited 1472 participants and completed the second wave of interviews and lab tests. Three doctoral students at UFC under the supervision of Professor Kendall
constitute the qualitative research team. The design of the guide used in this dissertation builds on the experience of the UFC team and their instruments. This dissertation study serves as a complement to the cohort study, building on previous research to permit to advance our knowledge of women’s responses to ZIKV. I developed several new instruments to complement the main study: a new rapid assessment guide to explore fertility decision-making; a case study guide to collect pregnancy narratives from women in Fortaleza affected by Zika.

2.6.2. The Study Environment

Data collection took place in two public health units, Posto de Saúde Graciliano Muniz and Posto Unidade de Saúde Escola Casemiro Jose de Lima Filho. These were clinics found in densely populated, low income level neighbors. These posts serve as primary care facilities for much of the population of Fortaleza. Services provided by these units include: appointments with physicians, nursing care, dental care, acute care, chronic care (hypertension, diabetes, leprosy, tuberculosis, HIV), prenatal and child care, dispensation of basic medicines, basic health exams, outpatient procedures (curatives, application of medication), prevention of gynecological cancer (colon, uterine, and breast), family planning and dispensing of condoms and contraceptives, rapid testing of HIV and syphilis, home visits, monitoring of beneficiaries of the Bolsa Família program, and health education group. These PHUs serve as central locations for prenatal care checkups, family planning services, and health education as well. During the ZIKV epidemic these PHUs were the source of repellent, contraceptives, and information for most of the population – especially those of middle to low class and recipients of Bolsa Família.
2.6.3. The Researcher

I have been working in the field of maternal and child health in Brazil for over five years. Previous work has been done with obstetric violence, healthy pregnancies, family planning, and optimal birth outcomes in Brazil. I have worked with *Rede Cegonha*, a national organization working to improve birth outcomes and women’s pregnancy experiences throughout Brazil, with extra effort placed in the Northeastern area of the country. Research projects have included topics such as: the scope of obstetric violence in Brazil (December 2014-February 2015), social determinants of obstetric violence and negative birth outcomes in Brazil (May 2015-August 2015), and the role of regionalism in women’s health (December 2015-February 2016). Throughout this time, I have honed my Portuguese language skills to a level of fluency.

Once the ZIKV epidemic appeared I was approached due to my background in the field to lead a multi-city qualitative exploration of women’s knowledge and perceptions of ZIKV in Brazil (May 2016- August 2016). Additional work has included partnerships with international organizations to evaluate the impact and programmatic experiences of organizations throughout the Caribbean and Latin America as a response to the ZIKV epidemic (November 2016 – December 2019). Having a medical anthropology background, has provided me with a strong qualitative background which has been a strength in this study. Being a female within the age range of the priority population was also a strength of the study as participants expressed that it allowed them to speak with me freely and feel comfortable. Throughout this time six trips to the field were completed.
CHAPTER 3: METHODS

3.1. THE STUDY

Most of the ZIKV research conducted to date has focused on the clinical side—diagnosis, etiology, and pathologies associated with ZIKV—leaving a significant gap in research related to the experiences and perceptions of those individuals most heavily affected by the epidemic. A brief search of published peer-reviewed sources shows fewer than 50 qualitative publications exploring ZIKV, with fewer than a dozen of those papers focused on Brazil (Arias, Tristan-Cheever, Furtado, & Siqueira, 2019; Borges, Moreau, Burke, Dos Santos, & Chofakian, 2018; Harvard Center for Reproductive Rights, 2018; Diniz, 2016, Marteleto, Weitzman, Coutinho, & Alves, 2017; Oliveira, Moreira, Maricélia, Lima, & Melo, 2018; Sousa, Mendes, Mufato, & Queiros, 2018).

Women’s response to the Brazilian authorities’ ZIKV recommendations is not well documented. Of the recommendations made, the most controversial concerned postponing pregnancy. There continues to be a lack of research pertaining to fertility intentions and family planning use during the ZIKV epidemic. Research needs to be conducted to better understand women’s fertility decision-making during the ZIKV epidemic and the contextual factors impacting those decisions. Qualitative methods allow researchers to explore the constitutive elements of a health issue while constructing a more robust explanation concerning the mechanisms perpetuating negative health outcomes. Given the controversial nature of the recommendations and uncertainty concerning the effectiveness of these recommendations, a formative and qualitative approach appeared appropriate.

This dissertation study serves as a complement to the ZIF cohort study, previously described. This study is building on previous research to advance our knowledge of women’s
responses to ZIKV. A niche this study aimed to fill was documenting ZIKV associated adverse pregnancies and children born with CZS.

3.2. TIMELINE

This study is composed of two segments: formative research and data collection. Formative research took place June 30, 2018-August 25, 2018 in Fortaleza, Brazil. This segment of the study included consulting with in-country partners, piloting data collection instruments, and reconnecting with individuals within the target population. This portion of time was also dedicated to meeting with members of the cohort study team and other professionals involved in ZIKV research within Fortaleza, Brazil. Initial findings from the cohort study and its previous RAA were assessed. Findings from this formative piece were utilized to enhance the design and contents of the data collection tools and create the final protocol for IRB approval.

Data collection took place between December 16th, 2018 – January 25th, 2019. With extensive help from the cohort study team members, the data for the rapid anthropological assessment and case studies were collected. Meetings with the cohort study team took place frequently to verify translations, compare results, and brainstorm next steps. Data analysis followed with this dissertation serving as the final report of the study. Once the dissertation is complete, all findings/reports/publishable items will be disseminated and shared with the cohort team and participants in the study. All participants and partners were made aware of anticipated documents to come from this study and will be contacted once those documents are ready to be distributed.
3.3. SUPERVISION AND STUDY TEAM

In-country partnerships with local researchers and individuals working with the cohort study substantially helped data collection in Fortaleza, Brazil. The study team facilitated the visits at the PHUs and aided in the recruitment of participants for this study. The Program Manager, Dr. Marto Leal, assisted in managing PHU staff, study team members, transportation, and recruitment scheduling. Students and nurses working within the PHUs were essential in assisting the interview process – they were the first contact for recruitment of participants, helped facilitate a secure location for conducting interviews, and allowed me to observe the resources and mechanisms at place within the PHUs. Frequent meetings with cohort staff and researchers took place throughout the duration of data collection. Findings were shared and compared to assess trends and outliers.

Research was first approved by the Federal University of Ceará IRB (FWA Reference # IRB00004330) for the cohort study. A letter of cooperation was obtained from Dr. Roberto da Justa, Chair of the Department of Community Health at the Federal University of Ceará, which authorized the PI to collect data in the PHUs and be supervised by Dr. Ligia Kerr as part of the cohort study. Tulane University School of Public Health IRB approval was granted December 16th, 2018 (IRB Reference # 2018-1606).

Throughout the study, graduate students at UFC were trained for an intensive period in qualitative methods. A significant portion of my time with the team included discussions on best practices in qualitative methods, the interview process, question development, interviewing techniques, and how to analyze qualitative data. PowerPoints, reading materials, and notes were shared with the team. Workshops on thematic analysis and NVivo software were conducted. This training bolstered the team’s skills to act as a feedback mechanism to discuss findings and next
steps in the exploration of topics. This training additionally aided in-country capacity building as well as professional networking. An example of training materials can be found in the Appendix.

3.4. RESEARCH QUESTION AND PROPOSITIONS

Included in this section are the overall goal for the research, key research questions, and propositions set forth by the study. Following Maxwell’s design strategy (2013) these questions are used to frame data collection, refine the purpose of the study, and enhance the validity of findings. They serve as topics to be explored more than questions to be put directly to respondents. Maxwell’s writing on qualitative research design suggests a Z-shaped path that starts with the researcher identifying the goal of the research, which leads a review of the literature to create the conceptual model which aids in the creation of the research questions. The content of the research questions then guides the methods selected for the research which corresponds to how methods will be checked for validity.

Previous experience in Brazil, specialization in maternal and child health, as well as experience within this community raised the researchers’ concerns that these recommendations would not be feasible for the target population. The overall goal of this study was established to explore this concern in greater depth as well as other findings from ZIF. Concerns around feasibility to recommendation adherence was echoed in popular media and peer-reviewed literature in sociology, anthropology, reproductive rights, as well as public health (Baum, 2016; Blanchard 2017; Diniz, D., 2017; Diniz, S., 2016; Harris, Silvermann, Marshall, 2016; Rasanathan, 2017; Schuck-Paim, López, Simonsen, & Alonso, 2016).

Review of these publications as well as literature on maternal-child health, disease transmission, and fertility decision-making led to the creation of the conceptual model. RAA and
case study methodologies were selected to divulge the constructs of the conceptual model. It should be noted that the already existing ZIF study infrastructure additionally helped offset resource limitations and additionally contributed to the selection of RAA and case study methodologies. Validity in qualitative work is conceptualized differently than that of quantitative measures, as qualitative best practices call for validity to be done via triangulation through comparing multiple sources and types of information. Findings from this study work to enhance the validity of findings from the ZIF cohort study.

Once the overall goal has been established, propositions follow to guide the research. Propositions are expected outcomes from the interviews, much as a quantitative researcher might express hypotheses. These questions and propositions aim to keep the research focused and analysis targeted, as well as to provide the reader with awareness as to the logic behind the study and the key concepts the research aimed to capture with data collection and analysis.

The overall goal of this study sought to understand:

- What role does ZIKV play in the lives of women and children in Fortaleza, especially as it pertains to the ZIKV prevention recommendations related to pregnancy and fertility decision-making made by Brazilian health authorities during the epidemic?
- Furthermore, how does ZIKV continue to play into the lives of women and children most severely impacted by ZIKV related adverse health outcomes?

To guide this research, the following propositions were developed to help organize the qualitative guide and research strategy. These propositions were developed from reviewing literature published during the ZIKV epidemic and an exploration of initial interviews from the
cohort study. Literature referring to initial quantitative and qualitative studies were reviewed, as well as editorials and comments left by Brazilian researchers and public health researchers familiar with Brazil’s history of battling outbreaks. Literature pertaining to behavior theory, health education and communication, maternal and child health, Brazil, and Zika virus perceptions and reactions were reviewed. Preliminary findings from ZIF’s qualitative component was reviewed to support the development of the propositions. Propositions were additionally modified according to results from the piloting of data collection instruments and initial interviews and conversations with in-country gatekeepers, potential key informants, and individuals from the priority population.

**ZIKV Recommendations and Response**

- What do women know about the ZIKV health messages and recommendations? What are women’s perceptions about the feasibility of ZIKV recommendations? What do they actually do to prevent ZIKV infection?

- **Proposition:** women’s knowledge of the recommendations, actionable behaviors that follow from the recommendations, and adherence to recommendations will all be incomplete. Important gaps will exist in their knowledge and performance of ZIKV related prevention behaviors.
Fertility Decision-Making during ZIKV

- Did, and are women currently, modifying their fertility decisions due to the ZIKV epidemic in Brazil? Why or why not?
  - **Proposition:** women did not, and are not, changing their fertility decision-making behaviors and are continuing their pregnancies. Primary reasons reported include gender norms, financial dependence, and their partners’ wishes.

Adverse pregnancies and children born with CZS in Fortaleza

- What were the experiences of women who had adverse pregnancies associated with ZIKV and their experiences raising children with Congenital Zika Syndrome?
  - **Proposition:** women who experienced adverse pregnancies or had children with CZS feel neglected and left without proper resources to manage lives affected by ZIKV.

3.5. SAMPLING

Participants for all components of this study were collected through purposive sampling. Research assistants on the ZIF study team contacted already enrolled ZIF participants (either via phone or in-person) and scheduled an interview to be completed with me. Interviewees were given monetary incentives that matched the amount given by other components of the study (money to cover transportation costs). This study used the same inclusion criteria as ZIF: women between the ages of 15-39, who live in one of the three designated communities in Fortaleza these clinics serve, who utilize the public health sector, who have engaged in sexual intercourse in the past year, and who have not been a recipient of tubal litigation. Sampling for case studies is described separately. Sampling continued until saturation was reached. Saturation was
achieved in terms of (1) interview data demonstrating sufficient repetition across interviewees and PHU locations, as well as (2) the variety of women’s experiences and demographic background (age, parity, number of children, exposure to ZIKV messaging, family planning use). The study originally anticipated approximately 15 interviews per each PHU. In total, 35 women were recruited for the RAA. Five of those women additionally took part in the case studies.

3.6. METHOD ONE: RAPID ANTHROPOLOGICAL ASSESSMENT

A Rapid Anthropological Assessment (RAA) is a form of Rapid Assessment Procedures (RAP). The RAA design incorporates several methods which may including semi-structured interviews, open-ended and in-depth interviews, structured and unstructured observations, ranking questions, free listing, scenarios, informal conversations in the study setting, as well as other types of formal qualitative methods (Kendall et al., 2005; Scrimshaw, Carballo, Ramos, & Blair, 1991). RAPs were originally used for the evaluation of agricultural extension workers and their programs (Rapid Rural Appraisal). Since then, anthropologists modified this approach to be used for health research (Scrimshaw & Gleason, 1992). The RAA has been used within a wide range of public health research topics including nutrition assessments, diarrheal disease, and HIV/AIDS research control programs (Helitzer-Allen, 1993; Kendall, 1983; Scrimshaw & Gleason, 1992). Within the realm of public health, RAAs have been utilized under several different names: Rapid Assessment Procedures, Targeted Intervention Research, and Focused Ethnographic Survey. RAAs are often utilized as formative research to inform programs, for evaluations, or to design health messages. When the RAA was developed it served as a contrast to conventional ethnography, serving as a time-limited approach to understanding social phenomena from an insider. This form of data collection deals with cultural nuances such as the
discrepancy between ideal or proposed behaviors in response to a problem versus the actual responses. Through contextualizing the problem and its solution, the RAA attempts to understand underlying patterns in a community using a mix of data collection methods such as interviews with members of the community and stakeholders, group interviews, and observation, conversations with community members, participant observations, focus groups, secondary data sources, and some structured questions such as demographic information. (Scrimshaw, 1992).

Scrimshaw comments that use of an RAA requires:

1. The researcher to be already familiar with the language and culture. The researcher should have already conducted research in the culture and should have a good understanding of customs, dialect, and behavioral meanings.

2. The researcher should work with a limited set of objectives or data collection guidelines. This permits focused work which can be carried out relatively quickly (Scrimshaw, 1992).

Due to my prior work in the study setting, previous work in maternal and child health issues in Brazil, and partnerships with similar priority populations, it was felt that an RAA would be an appropriate method for this dissertation. Due to financial constraints and a risk of harm due to a wave of violence in the city, copious time was also not available. The RAA and collaboration with the rest of the ZIF team to weigh in on gaps and patterns allowed this data to be collected in the allotted timeframe.
3.6.1 RAA: The Guide

The purpose of the RAA was to collect various forms of data, from numerous and diverse individuals. By capturing a diverse set of responses, through a diverse set of data collection methods, the RAA provided a wider understanding of the health issue and population of interest. The RAA was steered by a qualitative guide that was used for observations and in-depth interviews. Development of the guide was an iterative process, with several versions and modifications made throughout the piloting and data collection phases. Please see the Appendix for the final version of this study’s RAA guide. Guides were developed as a collective team effort of the cohort study. Development of the guide was based on extensive literature reviews, team members’ previous experience conducting qualitative research, knowledge of the study areas, and previous experience working with the population of interest. Previous guides from the cohort study were modified for this study. A large portion of the formative phase of this study (June -August 2018) was used to attend meetings with the cohort team to discuss successes and challenges with guides being used at that time. As this study’s guide was developed, it was piloted with individuals within the target population to check for any gaps, confusing questions, or misinterpretations. Throughout the interview process, new questions were added, questions were rephrased, and some questions were removed. The purpose of modifying this document was to ensure interviewees were comfortable and aware of what was being asked of them and that all components of the situation were assessed to best comprehend the scope of ZIKV and fertility perceptions.

The guide was semi-structured in nature and included topics such as: demographic and family information; knowledge, exposure, signs, and symptoms of ZIKV; pregnancy histories; reproductive intentions and family planning practices; mosquito avoidance/vector control;
attitudes and responses to ZIKV health recommendations; and care-seeking during the ZIKV epidemic. These open-ended questions allowed for an exploration of the factors relating to perceptions, behaviors, and behavioral intention during the ZIKV epidemic. Topics included: interactions with healthcare providers, reasons why women would or would not seek care or utilize care; perceived power within decision-making situations with their partner; perceptions as to how their friends/neighbors behave; and knowledge pertaining to how to protect oneself against ZIKV, where to go to obtain methods to protect oneself, how to utilize those methods, ease of utilizing those methods, and perceptions toward utilizing those methods to protect oneself against ZIKV. The guide additionally contained free listing exercises as well as questions asking women to rank the effectiveness of health behaviors, importance of health issues, and perceived risk of diseases. The final section of the guide included a series of ZIKV-specific scenarios. These prompts asked women to discuss their perceptions of the situation as well as how they believe their friends would act in each of the circumstances. Scenarios included concepts such as pregnancy, ZIKV prevention, ZIKV healthcare seeking, microcephaly, abortion, and partner dynamics.

It is essential that an RAA gather information from a diverse set of individuals within the priority population. This RAA included a range of women related to pregnancy intentions, marital status, age, housing, social class, education, and parity. This rapid assessment allowed for the identification of key informants and gatekeepers within the community which aided in the recruitment for the in-depth interview and pregnancy narrative components of this study. The RAA additionally allowed individuals in the community to become comfortable and familiar with my, thus allowing me to be less intrusive in this data collection process.
3.6.2. RAA: In-depth, Semi-Structured Interviews

These semi-structured interviews allowed a deeper insight as to women’s behaviors, attitudes, and perceptions related to the ZIKV epidemic and related health messaging, as well as the fertility decision-making process and reproductive health behaviors during the ZIKV epidemic. Data collection took place at either of the two PHUs: Posto de Saúde Graciliano Muniz or Unidade de Saúde Escola Casemiro Jose de Lima Filho. As previously mentioned, both were clinics operate under SUS and the Federal University of Ceará. Women were approached and the study was explained as well as what participation would entail. If the woman was interested in participation, the woman and interviewer moved to a separate, private room for the duration of the consent process and the conducting of the guide. This was done to maintain the participant’s privacy. Once in the private room, the participant was once again explained the purpose of the study and informed of her rights. A thorough consent process was conducted in Portuguese prior to data collection. Each potential participant was given a printed copy of the consent form to read and sign. All participants were able to read, and all signed a consent form prior to data collection. Interviewees were asked permission to audio record, but all declined. This was a foreseen possibility due to the potentially uncomfortable topics of abortion, sexuality, and reproductive health. The RAA interviews lasted between 30 – 120 minutes. At the end of each interview, a time was established for a follow-up phone call. A second phone interview took place 24 – 72 hours after the initial interview. The purpose of the follow-up was to verify data collected in the in-person interview, review the content of notes taken, and ensure the interviewee felt the data collected sufficiently represented their views.

The semi-structured format of the guide allowed for a more fluid navigation through the interview, the ability to add probes or questions, and the flexibility to remove irrelevant or
redundant questions. For example, when an interviewee was particularly enthusiastic about a portion of the guide, more probes were added, or the participant was asked for examples and anecdotes. This guide did contain potentially difficult questions related to abortion or negative health outcomes - therefore less pressure was put on these questions if it was apparent that the interviewee was uncomfortable. In these situations, I did take the opportunity to ask why the participants felt uncomfortable. This was particularly informative regarding the question around abortion because several women mentioned that they were worried a healthcare provider would report them to the police if they overheard the conversation. Information from piloting instruments and initial interviews also showed that income and economic considerations were important to informants and should be better included in the guide. These positive and negative reactions to questions allowed me to better deliver questions and better prepare the room in which the interviews were taking place, so interviewees felt more comfortable and secure.

Thorough fieldnotes were collected before, during, and after the interview. Fieldnotes were collected pertaining to date, time, place of the interview; specific facts, numbers, and details of what happened at the site; sensory impressions; interviewee’s and interviewer’s response to the interviewing process; the way the interviewee answers questions; body language during the interview; and specific words or phrases pertaining to the topic. Reflective notes on the interviews and personal experiences were also recorded daily. A weekly memo of thoughts, perceptions, and notions was created. All forms of notes were compiled into fairnotes (Halcomb & Davidson, 2006; Hill, 2003; Kendall et al., 2005). Fairnotes are comprehensive documents that include observations, fieldnotes, informal discussions with community members, and conversations among members of a research team. Composing fairnotes contextualizes the data into an organized, shareable document that depicts the interview conducted (Halcomb &
Davidson, 2006; Hill, 2003; Kendall et al., 2005). The process of creating fairnotes is analytic in nature as it synthesizes data to directly answer research questions. (Hill 2003; Halcomb & Davidson, 2006). Fairnotes are additionally advantageous as they are permanent documents that can be revisited, unlike audio recordings which must be deleted by IRB mandate.

3.6.3. Managing and Analyzing Data

Any paper data collected were stored in a locked case, with access granted only to the study team. Electronic data were stored on a secure, password-protected computer. Each participant was assigned ID numbers and pseudonyms which were used in any file names and documents. All files were saved and backed up on the Tulane University Box server which is HIPAA protected. A standard format for saving files and sharing files among the research team was used. No identifiers were used in the sharing of documents. To assist data management and analysis NVivo 12 Pro software was used. Regular meetings with the research team took place to ensure all documents were handled with care and findings were well documented, reported, and prepared. Documents utilized to aid in the management of the data collected included: a participant tracker (recruitment, interview, follow up), participant demographics file, a participant contact information list, a codebook, and typed versions of memos created in the field.

3.6.4. RAA: Analysis

Grounded theory was used as the systematic inductive method of conducting the research and analyzing the data of this study. This form of analysis allows a researcher to share patterns
through thematic observation to develop explanations and theories for why those patterns occurred (Gleason & Straus, 1967). Grounded Theory was chosen because it attempts to deconstruct an action or phenomenon to identify its phases, preconditions, properties, and purposes (Gleason & Straus, 1967; Charmaz, 2004). When discussing ZIKV there are two main “actions” that this RAA strives to deconstruct (1) ZIKV prevention and (2) fertility decision-making. By deconstructing these actions, the I strived to rebuild the conceptualization of these actions with a deeper understanding of the mechanisms motivating or impeding them. The analysis entails two phases of coding: axial (also referred to as open or initial) and focused (also referred to as selective). In the axial phase, line-by-line coding is applied to transcripts or complete guides, these codes are then honed and narrowed into categories through the second phase of focused-coding (Bernard, 2011; Charmaz, 2004).

Line-by-line coding was utilized on fairnotes which had been uploaded in NVivo 12 software. The analysis was additionally informed by the broad lens of Gender Theory so that the context of gender-charged, cultural norms were not forgotten or overlooked. Line-by-line coding connected data related to the women’s practices, beliefs, and attitudes toward ZIKV and ZIKV prevention- as well as their meanings, perceptions, actions, and words related to fertility decision-making. Trends and commonalities throughout the completed fairnotes created initial codes. These codes were then further assessed through the focused-coding phase where codes became categories that highlight key concepts that are used to address the research questions and propositions proposed in this study. From those categories, overarching themes were identified to demonstrate the key ideas that illustrated women’s experiences, perceptions, and behaviors related to ZIKV prevention and fertility decision-making.
3.7. METHOD TWO: CASE STUDIES

Findings from the RAA were utilized to inform the design and delivery of questions asked in the case studies. The case studies allowed a much deeper insight into women’s actual reproductive health behaviors as well as their experiences with pregnancy outcomes and childrearing pertaining to the ZIKV epidemic. To encapsulate a wide range of perspectives, a spectrum of ZIKV-specific fertility decisions, pregnancy, and outcomes was selected for each of the following situations: a miscarriage, a current pregnancy, a woman of higher socioeconomic status who had a child with CZS, a woman of lower socioeconomic status who had a child with CZS, and an abortion. Extreme cases of these outcomes were not desired as the goal of the study was to highlight cases which best reflected the experiential themes of women in similar situations. Women who participated in the RAA, had experienced one of the selected situations, seem eager to talk about the topic, and were willing to participate further, were asked to join the case study component of the dissertation. All five participants accepted. These case studies were assessed, evaluated, and handled on an individualized basis.

Only four of the case studies are included in this dissertation (the miscarriage, the current pregnancy, the woman of higher socioeconomic status who had a child with CZS, and the woman of lower socioeconomic status who had a child with CZS). The case study of abortion was removed from this dissertation as it was a unique case. As abortion is a criminalized act in Brazil, the topic comes with a complex, distinct set of issues that do not align with the aims of the study. It was decided to remove this case from this dissertation and allow it to be a more complete, separate manuscript that allows deeper discussion into abortion-specific issues separate from just ZIKV.
All case studies included five to seven in-depth interviews, lasting from approximately 70 to 200 minutes. These interviews were conducted in the participants’ homes or at a health care visit. Informal observations of interview settings and informal interviews with the woman’s family, friends, and community members were also collected. Audio recordings were declined. This was possibly advantageous as audio recordings may have hindered the opportunity for an honest, personal, and vulnerable discussion. Extensive notes were taken during the interview to serve as the basis for completed fairnotes. Interview notes and narratives were shared with participants to verify their meaning, content, and representation. Pseudonyms are used and small details were changed to preserve the privacy of the participants. At the completion of the data collection process, I presented a handwritten, personalized booklet to each of the participants documenting the story they shared.

3.7.1. Case Study Analysis

The case studies included in this study were used to delve deeper into the underlying cultural mechanisms. Pattern matching, explanation building, and time-series analysis were utilized in this dissertation (Yin, 2002). Pattern matching refers to the comparing and contrasting of expected outcomes or differing explanations. Patterns pertaining to women’s experiences with ZIKV prevention, infection, and outcomes were assessed. Explanation building is an explanatory analysis of the underlying phenomenon and its possible linkages. Women’s explanations as to their fertility decision-making behaviors, pregnancies, and childrearing were explored. Time-series analysis is an identification of the metamorphosis of themes overtime. Time was assessed to understand how experiences changed generationally, as the epidemic’s threat diminished, and as participants viewed their and their family’s futures. Fieldnotes then went through the same
process to create fairnotes, were uploaded into NVivo 12 Pro software, and were reviewed. Results were written in an ethnographic format. All ethnographies were read back to participants to check for consistency and respectable representation.

3.8. TRIANGULATION

Triangulation was an iterative and continuous process throughout the data collection and analysis of this study. Triangulation allowed me to modify and improve data collection and analysis by continuously cross-referencing information. Triangulation of the data collected in the RAA allowed for the synthesis of the information to produce themes and key information to allow for a deeper understanding of the health issue at hand. Triangulation allowed the PI to zoom in on this community and check for discrepancies between her and the community’s interpretation of the scope of the situation. Additionally, this triangulation provided an opportunity to cross-reference information provided from all forms of data collected. For example, the information women gave related to contraceptive availability at the PHUs was cross-referenced with the observational data on available contraceptives in the PHUs, and PHU worker’s perceptions toward the availability of contraceptives. Triangulation assessed the importance and priority of topics and questions on the interview guide, as well as how to best phrase those questions. This triangulation additionally allowed the PI to be better informed for the case study portion of the dissertation.
3.8.1. Observations

Observations included documentation of ZIKV-based health messaging and current programming in the study area, the healthcare facilities, pharmacies and supermarkets, media outputs, the community, and opportunities where participants demonstrated how they utilize these prevention tools (e.g. putting on mosquito repellent). Field observations were essential to better understand the context in which the priority population is meant to receive ZIKV information, assess their options, and make decisions. Observational notes taken in pharmacies and supermarkets pertained to costs of/differences in brands of items associated with ZIKV prevention such as condoms and mosquito repellent; trends in the types of people who frequent different stores; and where these locations were in relation to the city. Healthcare facility observations included types of resources provided, availability of services within the facilities, amount and types of individuals in the clinics, waiting times in the clinics, general behaviors of individuals inside the clinic, location within the community, physical features, and assets. Media such as music, television, radio, and social media (Facebook, Instagram, and Twitter) were viewed daily to understand how ZIKV and individuals associated with ZIKV were being represented and discussed. Media content, the creator of the media source, timing of media, how the media was shared, and people’s perceptions of the media were all documented.

3.8.2. Informational conversations

Informal, informational conversations included discussions with individuals within the community as well as people within the priority population. Informants included those close to the interviewee (mothers of interviewees, boyfriends, husbands, siblings, friends, cousins), as well as healthcare personnel (nurses, physicians, pharmacists, psychiatrists), and specialists
Conversations were casual information exchanges at typically unplanned encounters. Most conversations took place while carrying out observations or case studies. These discussions helped clarify differing perspectives of the epidemic and people’s response. For example, conversations with community members allowed a better understanding of who gatekeepers in the community were and how entities such as the PHUs were perceived.

Informational conversations were frequent as many individuals approached me to inquire as to the reason for my presence as well as what the research pertained to. People’s initial reactions to the study’s topic, advice they gave, and general feedback were unsolicited but useful in developing the scope of the situation in Fortaleza. For example, the reactions and comments nurses made regarding their perceptions of ZIKV in the priority population were important to note. Additionally, the ways in which men spoke of women or differentiated between groups of women (“good” vs. “bad”) were used to help the PI understand another view of the priority population. These informal conversations often accompanied the observations – for instance speaking with pharmacists about current repellent sales, speaking with bus drivers about the consistency of schedules, speaking with public health professionals about the types of sexual education they provide, and so on.
3.9. OUTCOMES OF ANALYSIS

This study and subsequent analysis are not without deliverables. The deliverables of this analysis are to:

- Provide community responses for the ongoing cohort study and detail community perceptions of ZIKV, Ministry of Health recommendations, and the recommendations’ effect.

- Capture contextual issues that affect response to ZIKV recommendations and ways to improve the response from the Ministry and authorities.

- Prepare a monograph that summarizes the public health implications of the community response to ZIKV and the perspectives of women on pregnancy, fertility decision-making, birth and child-raising in poor areas of Fortaleza during the ZIKV epidemic.

- Help to humanize the epidemic by capturing and sharing women’s stories and experiences during the ZIKV that may otherwise have been lost in the mostly clinically-driven approach to assessing the epidemic.
CHAPTER 4. Women’s Perceptions of ZIKV Prevention Recommendations: A Tale of Two Cities Within Fortaleza, Brazil (Manuscript 1)

BACKGROUND

Zika virus (ZIKV) reemerged as a global threat in 2015 with Brazil at its epicenter. The flavivirus can be transmitted by Aedes aegypti mosquito, through sexual intercourse, and from mother to child during gestation (World Health Organization [WHO], 2018a). ZIKV symptoms are like those of other common vector-borne diseases in the area – mild fever, headache, body ache, possible rash, and general malaise (Centers for Disease Control [CDC], 2018a). ZIKV’s ability to pass through the placenta during pregnancy (Adibi, Margques, Cartus, & Beigi, 2016) can lead to negative birth outcomes such as microcephaly, developmental issues, and difficulties with cognitive development. This group of ZIKV associated birth defects is termed Congenital Zika Syndrome (CZS) (CDC, 2018b; WHO, 2018b). There have been over 223,477 confirmed cases of ZIKV, approximately 60% of which have been reported in Brazil (over 137,288 cases) (Pan American Health Organization [PAHO], 2018). There have additionally been 3,720 confirmed cases of CZS, with over 2,952 of those cases found in Brazil (approximately 80%) (PAHO, 2018). A Public Health Emergency of International Concern was declared by the World Health Organization on February 1, 2016 (WHO, 2016a) then lifted on November 18, 2016 (WHO, 2016b). Although ZIKV incidence has decreased substantially, the virus continues as an endemic disease with local transmission in many areas of Brazil.

In response to the surge in cases of microcephaly, the Brazilian Ministry of Health created a set of recommendations for ZIKV prevention. These recommendations focused mainly on mosquito and pregnancy avoidance. These recommendations contrast those made by other global health authorities as Brazilian authorities poorly publicized the sexual transmission of
ZIKV and deferred the responsibility for family planning and reproductive health counseling to the clinics and healthcare providers (Ministério da Saúde, 2017; WHO, 2016c, 2016d).

Recommendations made by Brazilian authorities at the start of the epidemic appear to be reactionary and used existing recommendations urging women to: (1) have extensive prenatal consultations, (2) not consume alcohol or drugs, (3) not use medicines without medical advice, (4) avoid contact with people with fever, rashes or infections, (5) reduce mosquito breeding sites by removing containers that have standing water and adequately covering water storage receptacles; and (6) utilize mosquito protection such as keeping doors and windows closed or screened, wearing long-sleeved clothing, and using mosquito repellents (Fiocruz, 2015). As the scientific response expanded, recommendations and programmatic efforts began to focus primarily on mosquito avoidance and mosquito breeding site reduction. As a response to the epidemic, the Ministry of Education launched the “Zika Zero” program (Ministério do Educação, 2016) as a nested sub-program of the Ministry of Health’s national “Combate Aedes” mosquito elimination campaign (Ministério da Saúde, 2019). After the discovery of the virus’ sexual transmission (Counotte et al., 2016; D’Ortenzio et al., 2016), authorities put some effort into promoting condom use to prevent the spread of ZIKV. Health promotion and education pertaining to sexual and reproductive health at the time of ZIKV was minute compared to the effort placed on mosquito avoidance and breeding sites (Brito, 2016). The overwhelming majority of these recommendations were directed to individual women. Communal and governmental efforts to reduce breeding sites or control Aedes aegypti, if they existed, were not well publicized.

Although this paper argues that these recommendations are incomplete, it also acknowledges the many strengths in Brazil’s approach to ZIKV control and prevention. The
surveillance and information infrastructure already in place through the Unitary Health System (SUS) allowed for speed in Brazil’s ZIKV response and monitoring of the epidemic. The knowledge and skills embedded in Brazil’s scientific base rapidly led to the initial detection, monitoring, and coordinated epidemiological, clinical, and laboratory work associated with ZIKV infections and microcephaly cases in the Northeast of Brazil, providing a mechanism of action. This paper is not at all critical of that effort, but is critical of the manner in which public health education in response to a public health emergency was constituted, a problem shared by countries throughout the world that saw the response to ZIKV to be a simple and direct admonition that women not get pregnant.

METHODS

This study used qualitative methods to investigate how women in Fortaleza perceive ZIKV, the Brazilian authorities’ ZIKV prevention recommendations, and the feasibility of adhering to these recommendations. This study was nested in a larger cohort study “Zika em Fortaleza: respostas de uma coorte de mulheres entre 15 e 39 anos (ZIF)” (Zika in Fortaleza: responses of women 15-39 years old). Initial research approval was granted by the Federal University of Ceará IRB (FWA # IRB00004330) for the cohort study. Tulane IRB approval was granted December 16th, 2018 (IRB# 2018-1606). ZIF is led by principle investigator, Dr. Ligia Kerr, MD, MPH, PhD. and co-PI Dr. Carl Kendall, MA, PhD. The research team includes epidemiologists, biostatisticians, physicians, nurses, anthropologists, lab technicians, and doctoral students at the Federal University of Ceará (UFC) in Fortaleza, Brazil. ZIF includes qualitative, quantitative, and laboratory components. Women in the cohort completed a
quantitative survey and underwent a series of lab tests for the detection of ZIKV, dengue, and chikungunya exposure (IgG and IgM). The qualitative component uses a semi-structured open-ended research guide applied to a sub-sample of women in the cohort. The team is currently following 1,472 women. This study serves as a complement to the ZIF cohort study, building on the study to further explore women’s responses to ZIKV.

This study collected data utilizing a Rapid Anthropological Assessment (RAA). The RAA has been used in public health settings over the past 40 years under different names: Rapid Assessment Procedures, Targeted Intervention Research, Focused Ethnographic Survey, to name a few. RAA design draws from a list of methods including semi-structured, open-ended and in-depth interviews that are triangulated with structured and un-structured observations, free listing, scenarios, and other formal methods, and informal conversations in the study setting (Kendall et al., 2005; Scrimshaw, Carballo, Ramos, & Blair, 1991). RAAs have been used on a variety of research topics ranging from nutrition assessments, to AIDS research, to diarrheal disease control programs (Kendall, 1983; Scrimshaw & Gleason, 1992; Helitzer-Allen, 1993). In this study, the RAA was designed to use scenarios, free lists, case frame questions, and mix of qualitative and quantitative questions. The purpose of the RAA was to gather information from a diverse set of individuals within the priority population affected by Zika. The RAA included items related to their reproductive career and pregnancy intentions, relationship, marital status and pregnancy, their age and concerns for their “biological clock”, housing, social class, education and the precariousness of their living conditions. The RAA utilized in this study was built on the ZIF team’s previous instrument as well as preliminary findings from the cohort.

The core instrument used in the RAA was a qualitative field guide that included open-ended questions, free listing, and scenarios. The guide’s development was iterative and
incorporated feedback from pilot testing. The guide included: demographic and family information; knowledge, exposure, signs, and symptoms of ZIKV; pregnancy histories; reproductive intentions and family planning practices; mosquito avoidance/vector control; attitudes and responses to ZIKV health recommendations; and care-seeking during the ZIKV epidemic. Open-ended questions allowed for an exploration of the factors relating to perceptions, behaviors, and behavioral intention during the ZIKV epidemic. Topics included: interactions with healthcare providers, reasons for seeking or utilizing care; perceived power within decision-making situations with their partner; perceptions of their friends/neighbors’ behavior; and knowledge of how to protect oneself against ZIKV, where to go to obtain preventative materials, how to utilize those materials, ease of utilizing those materials, and perceptions toward utilizing those methods to protect oneself against ZIKV. The guide additionally contained free listing exercises as well as questions asking women to rank the effectiveness of health behaviors, the importance of health issues, and perceived risk of diseases. The final section of the guide included a series of ZIKV-specific scenarios. These prompts asked women to discuss their perceptions of the situation as well as how they believe their friends would respond in each scenario.

Formative research for this study took place June 30, 2018-August 25, 2018 during which data collection instruments were piloted, the ZIF team convened to strategize the study’s approach, and preliminary findings from the cohort study were shared. Throughout this period, graduate students at UFC were trained for an intensive period in qualitative methods and provided feedback to discuss findings and next steps in the exploration of topics. Data collection occurred between December 16th, 2018 – January 25th, 2019. The cohort study team recruited participants through purposive sampling. Research assistants on the ZIF team contacted already
enrolled cohort participants and scheduled an interview to be completed with this study’s PI. Sampling was continued until saturation was reached. The study originally intended a minimum of 15 interviews per data collection site. Saturation was achieved in terms of (1) variety in the background of women interviewed as well as (2) content area having sufficient repetition. Inclusion criteria were consistent with the ZIF study: women between the ages of 15-39, who live in one of the three designated communities in Fortaleza these clinics serve, who utilize the public health sector, who have engaged in sexual intercourse in the past year, and who have not been a recipient of tubal litigation.

Data collection took place in Fortaleza, Brazil in two public health units (PHUs), Posto de Saúde Graciliano Muniz and Posto Unidade de Saúde Escola Casemiro Jose de Lima Filho. These PHUs are a part of SUS and are overseen by UFC. These units serve as the primary location for basic healthcare, vaccinations, access to family planning, and pharmaceuticals. Interviews were conducted in private locations within the PHUs. Interviewees were asked permission to audio record, but all interviewees declined. This was a foreseen possibility due to the potentially uncomfortable questions on family planning, sexual practices, and abortion which both common and criminalized in Brazil. Thorough notes were taken during the interview and interviewees were followed up for a second phone interview within 24 – 72 hours of the initial interview. The purpose of the follow-up was to verify content and ensure all data collected adequately represented the interviewees. Completed interview guides were then written up as fairnotes (Hill 2003; Halcomb & Davidson, 2006). These completed guides were then coded. NVivo 12 Pro software was utilized to complete line-by-line coding and thematic analysis. These codes were narrowed into categories that highlighted key concepts used by respondents to
address the research questions. There were 136 codes identified, producing 16 overarching categories, which were organized by themes reported here.

RESULTS

This study recruited 35 women who completed interviews which lasted between approximately 30 – 120 minutes. The ages of the participants ranged from 18-39 years, with an average of 25 years. Of participants, 19 had children and 16 did not. Six of the participants in the study were pregnant at the time of their interview. All measures in Table 1: Participant Demographics are self-reported unless otherwise indicated.

Table 1: Participant Demographics

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>N= 35</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Age Range</td>
<td>18-39 years</td>
</tr>
<tr>
<td>Age Mean</td>
<td>25 years</td>
</tr>
<tr>
<td><strong>Number of Children</strong></td>
<td></td>
</tr>
<tr>
<td>Has children</td>
<td>n = 19</td>
</tr>
<tr>
<td>No children</td>
<td>n = 16</td>
</tr>
<tr>
<td>Range of number of children</td>
<td>0-7</td>
</tr>
<tr>
<td>Average number of children</td>
<td>2</td>
</tr>
<tr>
<td><strong>Currently Pregnant</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>n = 6</td>
</tr>
<tr>
<td>No</td>
<td>n = 29</td>
</tr>
<tr>
<td><strong>Disease Exposure</strong>(^1)</td>
<td></td>
</tr>
<tr>
<td>CHIK self-reported</td>
<td>n = 3</td>
</tr>
<tr>
<td>CHIK IgG test positive</td>
<td>n = 4</td>
</tr>
<tr>
<td>DENV self-reported</td>
<td>n = 1</td>
</tr>
<tr>
<td>DENV IgG test positive</td>
<td>n = 8</td>
</tr>
<tr>
<td>ZIKV self-reported</td>
<td>n = 6</td>
</tr>
<tr>
<td>ZIKV IgG test positive</td>
<td>n = 5</td>
</tr>
<tr>
<td>None</td>
<td>n = 17</td>
</tr>
</tbody>
</table>

\(^1\) Disease Exposure was recorded as either a blood test result or a self-report. IgG/IgM blood testing was provided by another branch of this cohort study; therefore, some participants had their results at the time of their interview. None of the participants had positive IgM results therefore only IgG results were recorded. If a participant did not have a test result, their self-reporting of exposure was recorded.
Self-reported socioeconomic class

In Brazil, socioeconomic class is calculated based on individuals’ ownership of household appliances, occupation, years of education, monthly income, and access to utilities. Socioeconomic class ranges from A (most affluent) to E (least affluent). The C-class is commonly perceived as the “middle class” encompassing the largest proportion of the population. A table of class distribution and characteristics can be found in the Appendices. The research team purposely approached women in the C-class to control for extreme differences in

---

2 Employment as used here includes having an official job card (Carteira de Trabalho) as well as part-time employment, informal employment, and self-employment. The category “unemployment” refers to women who self-reported having no form of occupation and/or no form of income.
income (A, B versus D, E classes). The classification of C suggests most individuals within this group solely utilize the public health sector, have an income above $3.152 reais a month, are mostly minimum wage earners, and have finished high school (Associação Brasileira de Empresas de Pesquisa, 2016). It was hypothesized that sampling women from the C class would include women who had the fiscal ability to adhere to recommendations, yet not be so affluent (classes A and B) that their experiences would not be comparable to many other women. It is also unlikely that women from classes A and B would use these SUS primary care facilities. Women in classes D and E previously interviewed in the larger ZIF study had reported both lower levels of information about the epidemic as well as less variety in options to prevent ZIKV.

It became evident in the piloting of the interview guide that it was common practice for people to identify as either high middle class (High C-class) or low middle class (Low C-class). Throughout interviews, women were eager to talk about differences in wealth, feeling there were major differences in lifestyle, access to goods, and stereotypes of people associated with either end of the class spectrum. Women commonly stated that the differences in class created two different versions of the same city - one for those of higher socioeconomic class (e.g. High C-class), and one for those of lower socioeconomic class (i.e. for this study Low C-class). While collecting demographic information, women were asked which class they identified with - all the participants identified as either High C-class or Low C-class. When we explored the class identity of the women in the sample, members of the health clinic staff clarified that many of these women who identified as Low C-class were actually poorer, in D-class. This may be due to social desirability or may be due to the women feeling they deserved to belong to a higher class stratification.
FINDINGS

Perceptions of Zika Virus

Participants were asked about their knowledge of ZIKV, signs and symptoms of the disease, where they acquired this information, and if they thought ZIKV was a problem. All interviewees were aware of ZIKV and associated it with a milder form of dengue. Only when associated with microcephaly or pregnancy was ZIKV viewed as more dangerous than other vector-borne diseases such as dengue, chikungunya, yellow fever, or malaria. Overall interviewees felt ZIKV was no longer an issue, having mostly disappeared after 2017. Respondents justified this low threat because of the media’s lack of coverage on the topic, the diminished number of cases in their neighborhoods, and the lessened emphasis of ZIKV in the healthcare setting.

“There was a lot of information on TV! A lot on the news and a lot of commercials talking about mosquitos and pregnant women…they looked like what we always see for dengue and [the news and commercials] even said zika is dengue so we thought ‘Ok I know dengue so I know zika so I will do nothing new’…and yes there was a lot about pregnancy and microcephaly which was very sad but if you are not pregnant you do not need to know, you know?”

(High C-Class, 18 years old)

“The television and Facebook had all the information about Zika…it was everywhere at the beginning but then it stopped, and we all figured Zika was over. Now you see nothing on the television or Facebook or WhatsApp so maybe it is gone.”

(Low C-Class, 22 years old)
Participants were then asked to share their feelings of ZIKV risk at the time of epidemic. Women who self-identified as a higher socioeconomic class felt they were at a slightly higher risk of exposure at the time of the epidemic, but currently felt removed from any risk. This lack of risk guided these women’s motivation to not adhere to ZIKV prevention behaviors. High C-class women believed that since their risk of ZIKV was low, there was no need to engage in ZIKV prevention, and that there were very little consequences of not adhering to the prevention recommendations.

“ZIKV is not a problem for us…. nobody is sick…no mosquitos…it's all good. Maybe in the favelas or in the pobreza there are still problems because they always have problems.”

(High C-class, 26 years old)

“Zika is gone by me so we are not worried and so what if you get it? Maybe you get a fever, but I think it is not a problem and I am not pregnant so why worry?”

(High C-class, 29 years old)

Women who identified as Low C-class initially said ZIKV was no longer a problem, but further discussion found there were still feelings of risk among this group. These participants had a high perceived risk of ZIKV during the epidemic and believed themselves to still be highly susceptible. Women in this group recalled feeling extremely vulnerable, helpless, and afraid during the epidemic. Most women in this group had contracted ZIKV or could identify individuals in their community who had ZIKV.

“Always people are sick…dengue…chikungunya…and now it's zika. You can work hard but the mosquito will win”
All 35 women interviewed recognized that not adhering to the prevention recommendations was risky yet argued that completing these behaviors came at a price. Associated costs tied to the ZIKV prevention included: repellent use being stigmatized, the financial burden of repellent, judgement for accessing condoms, condom use possibly alienating partners, and pregnancy avoidance leading to an unfulfilled life. When asked which was more important—the risk of ZIKV or the socioeconomic cost associated with the behaviors—all women said that the associated cost could more seriously affect a woman’s life. In the following quote the respondent discusses how ZIKV prevention doesn’t stand alone, but must be incorporated into one’s already existing list of responsibilities:

“I know ZIKV is bad if you’re pregnant, but now it is just another disease. For me...I need to buy food for my child first, pay for the car second, and a lot of other things before I think about using my money for repellent.”

ZIKV was viewed across interviews as mild and less impactful than the costs associated with adhering to preventative behaviors. This was found to be true in all situations other than in the context of a pregnancy. All respondents agreed that ZIKV prevention was incredibly important if a woman was pregnant due to the possibility of microcephaly or other negative birth outcomes. It was strongly believed that in this situation it was the mother’s job to protect the baby and ensure a healthy pregnancy. Pregnant interviewees felt extreme pressure to prevent ZIKV and subsequent harm to her pregnancy.
Feasibility of ZIKV Recommendations

A. Vector Control

Mosquitos

A portion of the interview guide touched on knowledge of mosquito prevalence and behaviors, attitudes toward mosquito control, and awareness of mosquito prevention recommendations. Women reported receiving their health information from news channels, television commercials, WhatsApp, and Facebook during the ZIKV epidemic. All informants were aware of mosquitoes’ ability to transmit ZIKV and other arboviruses such as dengue and chikungunya.

Participants recalled ZIKV portrayed in the media similarly to dengue and chikungunya. All interviewees recalled not pay much attention to the mosquito recommendations advertised because they had “already seen them all”, feeling it was not new information, but recycled dengue information with emphasis placed on pregnant women. Interviewees recalled ZIKV-specific messaging at the start of the epidemic, with a transition to just dengue information after a few months. Respondents assumed this transition symbolized ZIKV was gone and no longer a threat. Furthermore, women noted the consistent rainy-season-influx in mosquito media fostered complacency toward mosquito messaging, allowing them to ignore the redundant messages.

Content of mosquito prevention media listed by participants included general recommendations
for: repellent use, cleaning the home, and removing stagnant water. All women interviewed
expressed not feeling worried about mosquito prevention as they were cleaning their home daily
and felt knowledgeable about mosquitos. Women interviewed spoke of mosquitos as a common
occurrence, one which Brazilians expect to live with:

“Mosquitos are normal? (laughs) Yes mosquitos are our neighbors, they’re always
around and come back with the rain. Annoying but we are accustomed to it, you
know?”

(Low C-class, 32 years old)

The number of mosquitos within the community was perceived differently across socioeconomic
classes. High C-class interviewees did not perceive mosquitos as very prevalent, especially
during the dry season. Several women who identified as High C-class suggested they may not
see as many mosquitos because they live on higher floors of buildings, have fumigation services
in the community, or because they can close their windows due to access to fans and air
conditioning.

“I always see mosquitos when I walk on the street...not after they spray [fumigation]
.... but when I am in my apartment, we don’t have a lot [of mosquitos] in the house
because.... I don’t know because they don’t fly that high maybe? Or maybe because
we close the windows to use our air conditioning so they can’t get in.”

(High C-class, 37 years old)

In contrast, Low C-class respondents described their communities as full of mosquitos all year
round, especially during the rainy season. Interviewees mentioned living with mosquitos without
pause. Respondents who identified as Low C-class additionally mentioned needing to utilize
behaviors associated with facilitating mosquito breeding, such as storing water. Water storage was essential as piped water was inconsistent, purchased water was expensive, and rainwater could be used for house cleaning, pets, and washing cars. Purchased water was for consumption only. Low C-class interviewees associated their high number of mosquitos to be a result of the lack of cleanliness in the streets, piles of garbage in the neighborhood, or their neighbor’s unwillingness to tend to their home.

“I can clean my house all day and still mosquitos! I don’t think it is my house because

I am cleaning cleaning cleaning... I think it is because of my neighbor or because

there is so much trash in the streets that nobody picks up. Mosquitos like trash I

think.”

(Low C-class, 38 years old)

Cleaning the house

The recommendations targeting mosquito breeding site mitigation were generic, with no description of actionable behaviors. This left people in the community to find ways to fulfill the recommendations while important gaps existed, ultimately yielding ineffective results. An example of this is the communication focused on mosquito-based preventative measures (e.g. removing stagnant water, tending to the yard, eliminating trash) being promoted as “cleaning the home”. Recommendations instructed individuals to “clean your home”, focusing on hygiene as opposed to mosquito breeding site mitigation. This led women to assume general hygienic cleaning of the home (dusting, sweeping, removing garbage, washing floors) was the same as source reduction of breeding behaviors (use of larvicide, cleaning, covering water containers,
etc.). This suggests there exist gaps in knowledge of techniques needed to effectively mitigate mosquito breeding sites. All interviewees could identify cleaning “bad” or “dirty” water as mosquito mitigation methods yet could not explain how to clean to best prevent mosquitoes. When asked where this type of information was learned, respondents credited their mothers and television. These hygienic behaviors were believed to be an easy, learned response to growing up with the vector.

“No, I don’t think removing dirty water is hard. You know you need to clean your house in all these ways... no dirty water, no bad plants, no garbage, nothing dirty....and you do this every day to have a good home...a clean home... so I think if you do these things you should do every day then the maybe mosquitos won’t come.”

(High C-class, 26 years old)

Stigma was an underlying tone throughout these interviews, especially in its relation to women’s ability to mitigate mosquitos through cleaning their home. It became evident there existed negative perceptions or biases toward certain groups of people described as “poor”, “uneducated”, and “dirty”. All women interviewed, regardless of class, expressed biased views toward at least one of these stigmatized populations. It was found that being infected with ZIKV (adult or child) was associated with a person having a negative characteristic such as poverty, a lack of education, or a lack of hygiene. This concept was found in interviews across socioeconomic class.

“If a person is dirty or poor, I think they will be sick a lot because they are uneducated and lazy and don’t clean the house”

(High C-class, 29 years old)
“If you see a dirty home you know the woman is uneducated and poor, so she will probably be sick and have sick children”

(Low C-class, 23 years old)

Mosquito Repellent

Using mosquito repellent was universally viewed as important yet not utilized. Probing found that women felt repellent was an abnormal substance, using it was an uncommon practice, its odor was off-putting, and it was too expensive to purchase frequently. The idea of continuously utilizing mosquito repellent was believed to be unreasonable as this population has lived with mosquitos for generations with, what was perceived as, mostly mild consequences. It was mentioned that the smell of repellent may create the illusion that the user was ill or dirty.

“Yes, everyone tells us to use repellent, but we are not accustomed to it....and if you use it then you are smelly and sticky and that is not ok. Here in Brazil we need always smell good and look good – if we wear repellent people would think we don’t shower...or are sick or something”

(Low C-class, 31 years old)

B. Reproductive Counseling

None of the participants were aware of the recommendation to receive reproductive counseling if pregnant or contemplating pregnancy. Interviewees who were currently pregnant or had been pregnant during the outbreak reported not receiving counseling services. Healthcare staff at the
PHUs were additionally unaware of this recommendation. This is consistent with other studies which have documented reproductive counseling as a not widely mobilized aspect of the ZIKV response in Brazil (Wurth, 2017). Study participants were confused by the concept of reproductive counseling as it is often used for women who struggle to conceive, not women who are already pregnant. Additionally, the idea of planning a pregnancy was not perceived as normal. Meeting with a healthcare provider to design or schedule a pregnancy seemed unrealistic as pregnancies were often unplanned. When asked if reproductive counseling was a desired service, all respondents said no. Many respondents believed this counseling had no value since ZIKV, and microcephaly, had no cure.

"Is that normal? I have never heard of that. I don’t think women plan a pregnancy unless they have trouble becoming pregnant. I don’t know about that... I have never had that.... and why go if there is no cure for microcephaly?"

(Low C-class, 19 years old)

C. Sexual Transmission

Women were confused or dubious as to why the question about sexually transmitted ZIKV was asked in the interview. No participant was aware of the sexual transmission of ZIKV. Once the mechanism of transmission was explained, women continued to be confused and many became angry they had not been given this information earlier. Women explained feeling betrayed by health authorities because they had been given incomplete information that described ZIKV as “just like dengue”. An overwhelming majority of respondents suggested men be told this information immediately as they play a major role in this behavior.
“Is this true? (Angrily) Why didn’t anyone tell us? How are we supposed to be safe if men can make us sick? Men are always outside and never use repellent and are always complaining about mosquito bites….so then they get bites and we get Zika? That is not fair, you go tell them!”

(High C-class, 24 years old)

Condom Access

When asked about their ability to access and use condoms, women alluded to strict gender norms, crucial to adhere to in order to preserve one’s social status. Condom use was conceptualized as entailing two major behaviors: obtaining the condom and using the condom. Most interviewees felt it was a man’s job to obtain the condom from the pharmacy as this demonstration of sexuality was more socially acceptable, and because men were believed to have more financial means to purchase condoms. It was explained that a female purchasing condoms was suggestive of promiscuity and could open her up to potential rumors.

“Condoms are everywhere…. pharmacies have a lot of them I think….so boys can buy them there. He is the one who always wants sex and he is the one who works so he can buy it. If I go then I am a slut or people will think ‘why does her boyfriend not like her enough to get condoms, or maybe he has no job, she must be a bad quality girl’….and what if the pharmacist tells someone who tells my family? I am shy and I don’t want people saying bad things”

(Low C-class, 18 years old)
“Men decide to use condoms or not. If I have condoms waiting for him what will he think? He will think another man bought them!”

(High C-class, 28 years old)

Condom Use

The ease, necessity, and negotiation of condoms varied by socioeconomic class. High C-class women acknowledged men’s resistance to condom use but stated feeling confident, comfortable, and motivated to negotiate condom use. This was because condoms were thought of as a tool to postpone pregnancy, protecting her ability to continue her education and career. It was also noted that women of High C-class felt that if their partner respected them, he would be willing to grant their request to use a condom.

“Yes, you have to say ‘use it or I will leave’ because boyfriends don’t want to use it...never. But if he is a good man then he will use it. He will complain but he will use it. If he is a good boyfriend and respects you then he knows he needs to use it.”

(High C-class, 33 years old)

Most women in the Low C-class group reported not attempting condom negotiation nor condom use as they felt the situation was out of their control. It was believed that condom use was the partner’s decision as he had purchased the condom and needed to be the one to utilize it. Participants explained that advocating for condom use may lead their partner to suspect a woman’s infidelity or contraction of a disease. Condom negotiate was also perceived as precarious as it may appear accusatory of her partner’s loyalty. Interviewees were anxious that
advocating for condom use could lead their partner to become agitated, violent, withhold affection, remove monetary allowances, or abandon them.

“Oh, I don’t know... I am scared to try... I think he might become very mad and think that I am cheating on him. Men here get mad very quickly and it is very serious. Men will think you don’t love him or think you are a bad girlfriend. Maybe a man would hit the girl? Maybe he will leave? I don’t know... that would be the worst thing.... if he were to leave me with no love and no money for the house and children.”

(Low C-class, 32 years old)

D. Pregnancy Avoidance

Participants easily recalled the recommendation to avoid pregnancy during the ZIKV crisis as it had been something frequently advertised on the news and social media during the crisis. Although well-known, none of the women interviewed thought it was a serious recommendation. One woman stated:

“...it was serious? The government wanted all women to not get pregnant until you don’t know when... seriously? That is horrible! How can a whole country not have babies? Brazilians love babies!”

(High C-class, 24 years old)

All women interviewed voiced pregnancy avoidance as being unrealistic. Participants felt it was impossible to control the timing of a pregnancy, that pregnancy was God’s decision, and that it was unfair for authorities to direct family life. Respondents emphasized that for women around 30 years old it was important to not wait to have a child as their reproductive timeline
was approaching its end. High C-class women felt more able to prevent pregnancy as they had more family planning options and motivation to postpone pregnancy at the prospect of continuing education or furthering a career. Both groups, but especially the Low C-class group, felt pregnancy was an important aspect of life that was expected of all women. All women interviewed in this study felt socially pressured to have children by family, friends, and peers\(^3\). This recommendation was deemed unreasonable as it contrasted with what was believed to be within the control and desires of women interviewed.

**DISCUSSION**

The general argument of this article is that the ZIKV recommendations made were not constructed utilizing best practices in health education and promotion. By taking the Health Belief Model (HBM), one of the most commonly used health education approaches, we demonstrate what it yields as gaps in the communication. Since the HBM is so general in application, this model was chosen as an example of the minimum that could be done to apply best practices in health promotion and behavior change theory in an outbreak or epidemic setting. It is acknowledged that the HBM is an individual level model, therefore other factors at different levels need to be incorporated to develop an effective multi-level response.

This study’s findings echo results from other studies that suggest the ZIKV prevention recommendations did not consider cultural context nor socioeconomic class in their blanket health promotion (Ribeiro, 2018). A major finding of this study is how socioeconomic class

---

\(^3\) Pregnancy avoidance and fertility decision-making is discussed at length in this study’s other paper titled: *Fertility Decision-Making During the ZIKV Epidemic: Where is the decision?*
plays a major role in exposure, knowledge, perceptions, and adherence to ZIKV prevention recommendations. Self-reported class was associated with how women perceived the presence of ZIKV in their communities, the risk of ZIKV, their ability to access preventative materials, and the self-efficacy to adhere to the ZIKV prevention recommendations. High C-class women felt their affluence removed them from the risk of contracting ZIKV. This group also believed that if there was another outbreak, they had the fiscal means to adhere to recommendations. These perceptions led these women to have little motivation to attempt ZIKV prevention behaviors. Low C-class respondents felt there was a high likelihood of contracting ZIKV, yet generally felt unable to prevent ZIKV due to a lack of ability to access and utilize resources as well as a feeling of inevitability of contracting the disease. These factors dissuade these participants from attempting to prevent ZIKV. Both groups had a low willingness to engage in ZIKV prevention, but for different reasons.

**Perceived Benefits**

The main benefit of ZIKV prevention was to lower the likelihood of vertical transmission of ZIKV during pregnancy, to prevent CZS in newborns. If women were not pregnant, ZIKV prevention behaviors were not seen as beneficial. Engaging in mosquito control was perceived as beneficial as it mitigated the potential of contracting more severe diseases such as dengue and chikungunya. Cleaning the house was beneficial for aesthetic, hygienic reasons, and day to day functionality. Condom use was categorized as beneficial for general pregnancy postponement, but not for ZIKV prevention. Benefits for ZIKV prevention need to be better communicated so that prevention is seen as beneficial for both men and women- not solely for pregnant women.
**Perceived Barriers**

Barriers to ZIKV prevention identified in this study include financial constraints, fear of partner’s reactions, community pushback, complacency, social norms, feeling prevention was out of their control, and the repeated theme of inevitability of infection. The sense of inevitability of contracting a vector-borne disease was found to dissuade women from attempting ZIKV prevention behaviors. Participants felt certain of losing the battle against mosquitos due to the normalcy of cohabitating with the vector, the seasonal surge in exposure, neighbors not engaging in control measures, and city services not tending to sanitary measures, garbage disposal, or fumigation services. Respondents’ feeling of a lack of control was additionally a barrier in attempting to avoid sexual transmission of ZIKV and pregnancy. The barriers found in this study are consistent with other qualitative findings from Brazil during the epidemic (Elsinga et al., 2017; Linde, 2018, Center for Reproductive Rights, 2019). A more strategic health promotion response would identify barriers preventing recommendation adherence, then work with priority populations to overcome or mitigate the barriers.

**Perceived Risk**

This study asked women to retrospectively report their perceived risk of ZIKV at the time of the 2015-2016 crisis. It is acknowledged that reflective questions are challenging as people tend to remember the time more favorably than in its reality. It is important to understand this difference as it reflects how quickly individuals may forget the severity and susceptibility they felt when at highest risk. At the time of the crisis, both groups felt at risk of ZIKV, yet aside from pregnant women, there was currently very low perceived risk of ZIKV among women. The
similarity of ZIKV to other arboviruses, and belief that symptoms were mild, created a sense of low severity among respondents. All respondents felt their susceptibility had dropped since the end of the outbreak due to the decreased amount of ZIKV-specific media. These findings match results from qualitative work with ZIKV patients and nurses tending to patients in Brazil during the epidemic (Kristoffersson, 2017). Although ZIKV incidence has diminished, it is imperative to bolster ZIKV messaging so vulnerable populations are aware of their continued risk.

**Self-Efficacy**

Women who self-identified as Higher C-class assumed a high level of self-efficacy to avoid ZIKV. Although there was not a strong feeling of ZIKV risk, there was a strong feeling of being able to control whatever risk there was. Members of the Higher C-class group felt in future ZIKV outbreaks, they would be able to adhere to mosquito mitigation recommendations. Women in Low C-class had a diminished sense of self-efficacy to prevent mosquito bites due to: a lack of access to preventative materials, the need to store water, features of their housing structure, hygienic conditions in the community, and the normalcy of people within their social networks to be infected with similar endemic diseases such as dengue and chikungunya.

For condom use, the High C-class group felt a slightly higher sense of self-efficacy, but neither group felt completely able to obtain, negotiate, and use condoms. This is consistent with findings from focus groups of women during the 2016 ZIKV outbreak in Brazil (Marteleto, Weitzmana, Coutinho, & Alves, 2017). Women additionally struggled with self-efficacy over pregnancy avoidance due to social pressure to start a family and perceptions of difficulty around planning a pregnancy. Fear of stigma and community pushback additionally depleted participants’ self-
efficacy to adhere to these recommendations. It is important to understand enabling and deterring influences on self-efficacy as it can heavily influence an individual’s willingness to attempt ZIKV prevention.

**ZIKV Prevention Messaging**

The decrease in ZIKV messaging was believed to be a signal to stop ZIKV prevention behaviors. This disease has not disappeared therefore there is still a need for health education, media coverage, and ZIKV awareness efforts. Mosquito avoidance has become a complacent activity with vector eradication far from sight. Innovative and reinforced vector control recommendations should be disseminated to communities to aid them in their battle with *Aedes aegypti*. The repetitious nature of the mosquito messaging deterred participants from internalizing vector control information. Participants additionally felt desensitized to the recycled dengue information in the media. The lack of messaging about the sexual transmission of ZIKV created a lack of awareness and gaps in knowledge, placing women at a higher risk of acquiring the disease. This study finds that messaging for ZIKV prevention should not assume all women in Brazil, furthermore, the C-class, are in the same position to adhere to preventative behaviors. Messages need to be tailored to account for the different contexts throughout the socioeconomic strata in Brazil. ZIKV messages also need to be targeted toward men and male partners as they too play a role in the transmission and mitigation of the disease.
CONCLUSION

Recommendations made by health authorities during the ZIKV epidemic never intended to be a health communication program yet assumed they could influence behavioral change. Not using an evidence-based approach, such as HBM or another behavior change model or theory, creates generic, incomplete messaging for communities without direction as to actionable preventative behaviors. This leads to a lack of compliance and complacency in behaviors which create a domino effect of communities generating their own ideas to fill gaps in knowledge transmission, and prevention of diseases as has been documented in other outbreak ethnographies (Hewlett & Hewlett, 2008; Richards, 2016). Best practices in health education and promotion were overlooked, creating ineffective ZIKV prevention campaigns, and subsequent gaps in knowledge and behaviors. Outbreak and epidemic responses rarely utilize behavior theory in their design, creating missed opportunities for holistic approaches which consider enabling, deterring, and contextual factors which may impact adherence to preventative behaviors.

While the ZIKV epidemic might have lost importance due to decreased incidence of ZIKV and CZS, there now exists a new cohort of women becoming ready to be exposed to ZIKV and other arboviruses waiting in the wings. Developing effective strategies to capture and use community knowledge to design effective health promotion programming remains critical. This study suggests that women generally have a low willingness to engage in ZIKV prevention behaviors but for very different reasons. It is recommended that public health authorities adopt behavior change theory to better focus on critical gaps in the priority population to effectively respond to future public health threats.
CHAPTER 5. Fertility Decision-Making During the ZIKV Epidemic: Where is the decision? (Manuscript 2)

BACKGROUND

Zika virus (ZIKV) is a flavivirus transmitted primarily by mosquitoes, through sexual transmission, and in utero from mother to child (Centers for Disease Control [CDC], 2018a; World Health Organization [WHO], 2018a). A ZIKV outbreak that began in the northeast of Brazil in 2015 was quickly associated with a rise in cases of microcephaly by Brazilian scientists, prompting the World Health Organization to declare a Public Health Emergency of International Concern in February 2016 (WHO, 2016). The most notable outcome of ZIKV infection is its transplacental transmission possibly leading to Congenital Zika Syndrome (CZS) – a panoply of birth defects that includes microcephaly, blindness, cognitive impairment, brainstem dysfunction, congenital issues, and deafness (CDC, 2018b; WHO, 2018b). ZIKV’s mechanisms of transmission, extent of symptoms, and ability to harm were being investigated in real-time with the epidemic, as researchers were unfamiliar with the virus and the extent of its ability to damage mothers, fetuses, and newborns.

ZIKV prevention recommendations put forth by the Brazilian Ministry of Health primarily focused on mosquito vector control as well as recommendations for women to avoid pregnancy (Ministério da Saúde, 2017). The Brazilian Ministry of Health’s – as well as several other international and national health authorities - recommendation to avoid pregnancy was driven by uncertainties surrounding fetal effects accompanying the ZIKV epidemic. Given the state of knowledge of the virus and transmission, potential alternative etiologies, difficulty diagnosing fetal effects, and a lack of fetal interventions beyond abortion, not getting pregnant seemed the only reasonable response. Left unconsidered in this recommendation were
considerations of context: women’s control over conception and its inherent uncontrollability, individual and societal demographic expectations, and numerous other factors related to a decision, if one is taken, to get pregnant and carry to term.

While the recommendation and its ex-cathedra proclamation was not designed to be sound health communication, women were instructed to respond. Increasingly, in emerging infectious disease epidemics health authorities attempt to translate epidemiological findings directly into recommendations to impose on populations. In the case of Ebola, as monographs Richards (2016) and the Hewletts (2008) have demonstrated, it was local knowledge, not pronouncements from centralized authorities, that provided solutions. This paper follows a similar strategy, examining how Brazilian women in a large city in the northeast of Brazil perceive fertility decision-making, how women conceptualize and weigh factors pertaining to fertility desires, what women’s fertility decisions have been in the three years following the outbreak of the ZIKV epidemic, and if, and how, ZIKV influenced their fertility decision-making process.

Stratified Reproduction

Stratified reproduction is a concept from Shellee Colen that embodies the feminism of Inhorn, Rapp, and Ginsburg (Colen, 1995; Rapp & Ginsburg, 1995). Stratified reproduction asserts there are imbalances in the ability of people of different races, ethnicities, classes, and genders to reproduce, exercise their reproductive rights, and nurture their children (Colen, 1995; Rapp & Ginsburg, 1995). This framework states that women often do not have a choice in their fertility decision-making process due to factors such as societal standards, social expectations, and wealth lessening the woman’s power. Stratified reproduction argues that society’s
normalization of motherhood and determination of what womanhood “should be,” can further reduce women’s power within the fertility decision-making process (Colen, 1995; Rapp & Ginsburg, 1995; Inhorn & Balen, 2002).

This theory posits that society overestimates the agency women have within their lives, relationships, and reproductive decisions. The ZIKV prevention recommendation to postpone pregnancy neglects the challenges facing women situated in a context which denies them reproductive autonomy, and – in its monotone uniformity- assumes the reproductive lives of women throughout Brazil are homogenous. Several feminist scholars have responded to the ZIKV epidemic by suggesting stratified reproduction as a frame of reference to best acknowledge differences in women’s ability to respond to ZIKV prevention (Harris, 2016; Johnson, 2017; Stern, 2016). This concept is applied to the discussion of the study as it encapsulates a more comprehensive collection of factors and their interactions- differences in geographic, political, economic, structural, and social influences - which are hypothesized to affect women’s desire and ability to avoid pregnancy. Aligning with this concept, this study hypothesized that differences in a woman’s socioeconomic class create differences in access, barriers, and the ability to adhere to fertility intentions. When investigating the recommendation for women to avoid pregnancy or manage their pregnancy intentions in the wake of the ZIKV epidemic, it is important to understand how women in different contexts conceptualize fertility decision-making and are willing and able to act on it.
Fertility Changes in Brazil

Fertility rates were at a turning point in Brazil before the ZIKV epidemic. In the 1960s Brazil’s total fertility rate was estimated at 6.3 children per woman – since that time, the rate has steadily declined due to enhanced access to family planning, improvements to newborn care, increased female education, and rising feminist movements (Caldwell, 2017). Brazil’s current fertility rate is below replacement at 1.7 children per woman (Instituto Brasileiro de Geografia e Estatística, 2016). The nationally representative survey, *Pesquisa Nacional de Demografia e Saúde da Criança e da Mulher [PNDS]* (National Survey of Demography and Health of Women and Children) found that 55% of all pregnancies in Brazil were unintended; on average, women from the northeastern areas have the highest fertility rates; women with low education typically have double the national average of children (4 children compared to 1.7); and fertility rates were higher among self-identified nonwhite women than white women (PNDS, 2006). Although declining nationally, these statistics suggest that there exist disparities among groups yielding an unequal decline in the fertility rate, along with unequal gaps in access to contraceptives, family planning knowledge, reproductive autonomy, and comprehensive sexual education.

Fertility declines in the southern areas of Brazil followed increases in development, education, and wealth – improvements whose impact has not yet reached the north and northeast regions. Additional factors that have been identified with differing fertility rates include variations in adherence to gender norms, religious ideologies, access health services, health literacy, and availability of contraceptive methods (Marteleto, Weitzman, Coutinho, & Valongueiro Alves, 2018). Socioeconomic status, or class, should be considered when assessing fertility trends in Brazil. The class structure in Brazil is calculated based on individuals’ ownership of household appliances, occupation, years of education, monthly income, and access
to utilities. Class positions range from A to E - whereas A is the most affluent class and E is the least affluent class on the scale (Associação Brasileira de Empresas de Pesquisa [ABEP], 2016). Thinking of a bell-shaped curve, the C-class is “middle class” constituting almost 50% of the population in Brazil (ABEP, 2016). An income and wealth classification of C suggests individuals of that class primary use the free public health sector, have an income above BRL 3.152 reais a month, and have finished high school. Many in the C-class finished some university or have a technical degree and work in occupations such as cashiers, teachers, managers, and mechanics (ABEP, 2016). Within the C-class exist groups C1 and C2. Those in the C1 group are slightly more affluent with a Brazilian Criteria Threshold of 23-28 points as compared to the C2 group which has a threshold of 17-22 points (ABEP, 2016). The demographics makeup of Fortaleza is primarily comprised of those in the C1 group (15.0%), C2 group (26.1%), and D/E group (38.4%). In this paper, participants’ socioeconomic class will be referred to as either “High C-class” or “Low C-class” as this is how participants self-identified their class position. A table of economic class distribution and characteristics can be found in the Appendix.

Fertility and ZIKV

The North and Northeastern areas of Brazil were at the epicenter of ZIKV and its fetal effects. Additionally, most of the women at risk for unplanned pregnancies lived in Northeast Brazil in areas of high ZIKV prevalence during the first years of the epidemic (Schuck-Paim, López, Simonsen, & Alonso, 2016). In June 2016, a national questionnaire was administered in Brazil, recruiting over 2,000 women between the ages of 18-39. The study by Diniz, Medeiros,
and Madeiro explored women’s pregnancy intentions during the ZIKV epidemic and found that 56% of women reported they had avoided or tried to avoid pregnancy due to the ZIKV epidemic (2017). Furthermore, the study found that 66% of women from the Northeastern region of Brazil reported wanting to avoid pregnancy due to ZIKV but felt they did not have total control over that decision due to an unmet need for family planning resources, societal or interpersonal pressure to conceive, and unequal power dynamics within a relationship (Diniz, Medeiros, & Madeiro, 2017).

Fertility rates have not drastically changed since the ZIKV epidemic, contrary to what researchers hypothesized during the crisis. According to projections by Castro, Han, Carvalho, Victora, and França (2018) the fertility rate between September 2015 to December 2016 in Brazil showed a deviation of only 119,095 births from estimates. This lack of reaction may be associated with a lack of awareness of this recommendation, women not wanting to change their pregnancy intentions, or women being unable to change their fertility decisions. This paper seeks to sort out these reasons and understand how women in this study conceptualize fertility and fertility decision-making within the context of ZIKV. Qualitative methods were utilized in this study to answer the following research question: Did, and are women currently, modifying their fertility decisions due to the ZIKV epidemic in Fortaleza, Brazil? This study explores how women perceive fertility decision-making, factors which may impact fertility decision-making, if/how gender norms impact these decisions, and the role of social class in these decisions.
METHODS

This qualitative study sought to explore women’s fertility decision-making as it relates to the ZIKV epidemic, their beliefs of social norms around pregnancy, attitudes toward motherhood, and their contraceptive access, utilization, and perceptions. This study was nested within a larger cohort study, *Zika em Fortaleza: respostas de uma coorte de mulheres entre 15 e 39 anos (ZIF)* (Zika in Fortaleza: responses of a cohort of women 15-39 years old⁴). ZIF includes a qualitative component, a quantitative survey, and a lab component that tests for exposure to Zika virus, dengue, and chikungunya. The cohort study is based in Fortaleza, Brazil and is directed by principle investigator, Dr. Ligia Kerr, MD, MPH, PhD. and co-PI Dr. Carl Kendall, MA, PhD. The research team includes anthropologists, biostatisticians, epidemiologists, lab technicians, nurses, physicians, and doctoral students from the Federal University of Ceará (UFC). The research team is currently following a cohort of 1472 women. This nested study serves as a complement to the ZIF cohort study, as it allows a deeper understanding of women’s responses to ZIKV- specifically, women’s fertility decision-making as a response to the epidemic.

A Rapid Anthropological Assessment (RAA) –also sometimes labelled Rapid Assessment Procedure, Targeted Intervention Research, or Focused Ethnographic Survey- was utilized in this study. This method was selected due to the relative brevity of fieldwork, the use of multiple methods of data collection, relatively large sample size for qualitative research, ease of administration by trained fieldworkers, and consistency of interview formats for analysis. RAAs apply methods such as semi-structured, in-depth interviews, observations, free listing,

⁴ Initial research approval was granted by the Federal University of Ceará IRB (FWA # IRB00004330) for the cohort study. Tulane IRB approval was granted December 16th, 2018 (IRB# 2018-1606).
scenarios, and other formal and informal methods which can then be triangulated (Bernard, 2004; Gove & Pelto, 1994; Helitzer-Allen, Allen, Field, & Dallabetta, 1996; Kendall et al., 2005; Kumar, 1993; Scrimshaw, Carballo, Ramos, & Blair, 1991).

Several guides had been developed for ZIF. In this study, a guide was designed to use scenarios, free lists, ranking, case frame questions, and a mix of qualitative and quantitative questions. The RAA data collection instrument used covered content such as: demographic information, pregnancy histories, reproductive intentions, family planning practices, attitudes and responses to ZIKV health recommendations, and care-seeking during the ZIKV epidemic. The guide additionally contained questions regarding women’s perceptions toward ZIKV prevention behaviors, conceptualization of ZIKV, and perceived risk of the disease. The final section of the guide was a series of ZIKV-specific scenarios which walked participants through ZIKV-specific situations, asking them how they believe their friends would act in each of the circumstances. Scenarios walked participants through situations around pregnancy, ZIKV prevention, ZIKV healthcare seeking, microcephaly, abortion, and partner dynamics. The RAA guide used can be found in the Appendix.

The guide was developed iteratively to incorporate feedback from pilot testing, feedback from study team members, and the ZIF principal investigators. Formative research for this study took place June 30, 2018-August 25, 2018. Formative research included strategic meetings with the ZIF team, intensive qualitative training of UFC graduate students, and piloting of RAA instruments. All of this was done to create feedback mechanisms for this qualitative study, so that data collection, findings, and analysis could be directed, discussed, and evaluated within the ZIF cohort.
Data collection took place between December 16th, 2018 – January 25th, 2019. The cohort’s research assistants contacted already enrolled ZIF participants via phone or in-person to participate in this nested study. The consent for the original ZIF study included the ability for ZIF to contact participants about future research opportunities. Inclusion criteria for this study were consistent with the ZIF study: women between the ages of 18-39, who live in one of the three designated communities in Fortaleza these clinics serve, who utilize the public health sector, who have engaged in sexual intercourse in the past year, and who have not been a recipient of tubal litigation. Sampling was done until saturation was reached – for this study saturation was determined by the (1) variety of women’s backgrounds as well as (2) ample repetition in responses to the guide’s content area. The study originally sought to conduct 15 interviews at each of two public health units (PHUs), Posto de Saúde Graciliano Muniz and Posto Unidade de Saúde Escola Casemiro Jose de Lima Filho. These PHUs are a part of the Unified Health System (SUS) and are overseen by the School of Medicine of the Federal University of Ceará. These clinics are located within the community and serve as the primary location for basic healthcare.

Consent was obtained by the PI of this study prior to data collection. All participants consented to this study. As was foreseen, permission to be audio-recorded was not given by the participants. The study team anticipated this due to the sensitive nature of topics discussed such as intercourse, family planning, religion, and abortion. Consent and interviews were conducted within a private location within one of the selected PHUs. Thorough notes were taken during the interview and a follow-up phone interview took place within 24-72 hours to confirm the accuracy of data collected. The extensive interview notes were merged with fieldnotes, expanding the documents into fairnotes, which were then finalized into a set of completed
guides. Fairnotes included observations, fieldnotes, and research team conversations used to contextualize findings. Fairnotes were utilized as they provide a way to organize the plethora of data into an all-encompassing, shareable document that holistically represent the interview conducted (Hill 2003; Halcomb & Davidson, 2006). The completed guides were uploaded to NVivo 12 Pro software where data were line-by-line coded (Charmaz, 2006; Creswell, 2013). These codes were narrowed into categories then themes of concepts which addressed the research questions posited by the team.

RESULTS

The sample size for this study was 35 women. The average age of participants was 25 years old with a range of 18-39 years. Six participants were pregnant at the time of their interview, 19 had children, and 16 had no children. Duration of interviews ranged from approximately 30 to 120 minutes. All measures in Table 1: Participant Demographics are self-reported unless otherwise indicated in the footnotes.

Table 1: Participant Demographics

<table>
<thead>
<tr>
<th>Demographic Characteristic</th>
<th>N= 35</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Age Range</td>
<td>18-39 years</td>
</tr>
<tr>
<td>Age Mean</td>
<td>25 years</td>
</tr>
<tr>
<td><strong>Number of Children</strong></td>
<td></td>
</tr>
<tr>
<td>Has children</td>
<td>n = 19</td>
</tr>
<tr>
<td>No children</td>
<td>n = 16</td>
</tr>
<tr>
<td>Range of number of children</td>
<td>0-7</td>
</tr>
<tr>
<td>Average number of children</td>
<td>2</td>
</tr>
<tr>
<td><strong>Currently Pregnant</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>n = 6</td>
</tr>
<tr>
<td>No</td>
<td>n =29</td>
</tr>
</tbody>
</table>
### Disease Exposure

<table>
<thead>
<tr>
<th>Disease Exposure</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIK self-reported</td>
<td>n = 3</td>
</tr>
<tr>
<td>CHIK IgG test positive</td>
<td>n = 4</td>
</tr>
<tr>
<td>DENV self-reported</td>
<td>n = 1</td>
</tr>
<tr>
<td>DENV IgG test positive</td>
<td>n = 8</td>
</tr>
<tr>
<td>ZIKV self-reported</td>
<td>n = 6</td>
</tr>
<tr>
<td>ZIKV IgG test positive</td>
<td>n = 5</td>
</tr>
<tr>
<td>None</td>
<td>n = 17</td>
</tr>
</tbody>
</table>

### Self-Reported Socioeconomic Class

<table>
<thead>
<tr>
<th>Class</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>High C-class</td>
<td>n = 18</td>
</tr>
<tr>
<td>Low C-class</td>
<td>n = 17</td>
</tr>
</tbody>
</table>

### Relationship Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>n = 13</td>
</tr>
<tr>
<td>Relationship</td>
<td>n = 12</td>
</tr>
<tr>
<td>Married</td>
<td>n = 10</td>
</tr>
</tbody>
</table>

### Education

<table>
<thead>
<tr>
<th>Education</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some secondary school</td>
<td>n = 10</td>
</tr>
<tr>
<td>Completed secondary school</td>
<td>n = 11</td>
</tr>
<tr>
<td>Some college</td>
<td>n = 6</td>
</tr>
<tr>
<td>Completed college</td>
<td>n = 8</td>
</tr>
</tbody>
</table>

### Occupation

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>n = 28</td>
</tr>
<tr>
<td>Unemployed</td>
<td>n = 7</td>
</tr>
</tbody>
</table>

### Residential Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natal Family</td>
<td>n = 22</td>
</tr>
<tr>
<td>With Partner</td>
<td>n = 13</td>
</tr>
</tbody>
</table>

### Religion

<table>
<thead>
<tr>
<th>Religion</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catholic</td>
<td>n = 27</td>
</tr>
<tr>
<td>Evangelical</td>
<td>n = 8</td>
</tr>
</tbody>
</table>

### Religiosity

<table>
<thead>
<tr>
<th>Religiosity</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Religious</td>
<td>n = 9</td>
</tr>
<tr>
<td>Somewhat Religious</td>
<td>n = 14</td>
</tr>
<tr>
<td>Religious</td>
<td>n = 8</td>
</tr>
<tr>
<td>Very Religious</td>
<td>n = 4</td>
</tr>
</tbody>
</table>

---

5 *Disease Exposure* was recorded as either a blood test result or a self-report. IgG/IgM blood testing was provided by another branch of this cohort study; therefore, some participants had their results at the time of their interview. None of the participants had positive IgM results therefore only IgG results were recorded. If a participant did not have a test result, their self-reporting of exposure was recorded.

6 *Employment* as used here includes having an official job card (*Carteira de Trabalho*) as well as part-time employment, informal employment, and self-employment. The category “unemployment” refers to women who self-reported having no form of occupation and/or no form of income.
Socioeconomic Class

As recruitment took place at the PHUs, it was likely that those utilizing the free public healthcare would be members of classes C, D, and E. It became apparent in the recruitment process that most women identified as members of the C-class. This was found to be advantageous as it allowed this study to further serve as a compliment to the ZIF study where primarily D and E class individuals had been recruited. This research study posited that differences in socioeconomic status or class impact a woman’s fertility decisions, fertility decision-making power, and fertility desires. This study attempted to explore the “middle class” or C-class as it is hypothesized that within this assumed homogenous class, there still exist differences in fertility decisions due to socioeconomic class divisions within the C-class. Additionally, it was hypothesized that C-class women would include women who had more freedom and the financial resources to pursue their reproductive intentions than women of the D or E class. This hypothesis was confirmed by initial findings from the larger cohort study which documented D and E members discussing having little access to information, family planning, and ability to access of ZIKV prevention material.

In the piloting of the instrument, it became apparent to the interviewer that there were sharp differences in responses to socioeconomic class. Participants consistently identified as either high middle class (High C-class) or low middle class (Low C-class). High C-class women reported feeling more affluent, separating themselves from the lower middle class and classes D and E. These higher middle class women often had professional jobs, had completed more years of education, and owned expensive items such as a car. Women who self-identified as Low C-

---

7 Members of the health clinic staff noted that several women who identified as Low C-class were technically members of the D-class. This assessment will include how women self-identified their class as this is hypothesized to be more important to women’s perceptions than their actual class status.
class felt not as affluent and described barriers to obtaining higher middle class status. These participants were employed in lower-paying positions, had fewer years of or no professional school education and, lacked items such as a new phone or a car that would cement their status in the higher middle class. These class differences played out in the responses to many items in the guide, as presented below.

FINDINGS

I. Fertility Decision-Making

A. Recommendation for Counseling Services

Contrary to the WHO and Brazilian Ministry of Health’s recommendation to receive reproductive counseling amidst the threat of ZIKV, none of the respondents recalled receiving these services. Women who had been pregnant in the last three years, or were currently pregnant, were probed further to see if any form of such discussions took place during their clinical visits prior to, during, or after their pregnancies. Respondents reported having no such discussions. It was furthermore shared that reproductive counseling was negatively perceived as women were unfamiliar with the concept, believing it was an undesirable service only provided to women if they were having trouble conceiving. This finding is consistent with both qualitative and quantitative studies which reported a national gap in reproductive counseling during the ZIKV crisis (Borges, Moreau, Burke, Dos Santos & Chofakian, 2018; Wurth, 2017).
Conceptualizing Family Planning

Women expressed confusion when presented with the notion of planning a pregnancy. The idea of determining a course of reproductive action with one’s partner was universally characterized as negative, strange, and uncomfortable.

“What do you have to plan? When you are pregnant, you are pregnant... and then you just try to be healthy.”

(High C-class, 37 years old)

“What do you decide? You don’t sit down with your boyfriend and pick a day to be pregnant? That is crazy...”

(Low C-class, 20 years old)

All women insisted that speaking bluntly about these concepts would alienate their partner. This type of communication was believed to be sneaky, deceptive, or indicative of having alternative plans of infidelity or abandonment. Male partners were believed to have a strong desire for children, commonly advocating for a larger family. Women unanimously voiced that expressing a desire to not have children or postponing a pregnancy would be met with backlash from a partner as it was an action associated with not loving the partner, not being a good wife, being a bad mother, or being cruel.

“If I said I wanted to plan a pregnancy my boyfriend would think I have a secret plan...he would think I was with another man or was trying to leave him”

(High C-class, 19 years old)
“A woman can’t just say I don’t want to be pregnant...you need to be sweet about it
and nice or else you appear as if you are cold or don’t want to be a mother...just
rude...no it is not good to do that...”

(High C-class, 33 years old)

Male partners’ unwillingness to engage in family planning discussions, postpone a pregnancy, or utilize condoms were barriers identified by participants. This is consistent with other studies which documented women’s challenges with their partners’ unwillingness to use condoms during the ZIKV epidemic (Borges, Moreau, Burke, Dos Santos, & Chofakian, 2018; Marteleto, Weitzman, Coutinho, & Valongueiro Alves, 2018).

B. Recommendation to Postpone Pregnancy

Interviewees recalled the recommendation to postpone pregnancy due to ZIKV being featured frequently on the news at the start of the epidemic. None of the interviewee thought this recommendation was reasonable. After explaining that this recommendation was suggested to all women in Brazil, respondents felt confused and angry:

“I don’t believe it...why would they say that? People need to live! The government
knows nothing and cannot tell me what to do!”

(Low C-class, 20 years old)
“I don’t think anybody would listen to that. That is not fair. I cannot have children until they decide I can? What if I want to have children, will I be punished? And if women don’t listen... are we to blame for bad outcomes? That is not fair!

(Low C-class, 27 years old)

Social Expectations

Many respondents felt postponing pregnancy was often impossible due to the pressure Brazilian women are under to become mothers. It was consistently stated that motherhood was perceived as an important, positive, meaningful aspect of a woman’s life. Interviewees insisted that all women wanted to be mothers, that Brazilian culture was very family-oriented, and that children were an essential part of a Brazilian life.

“Everyone loves babies! Especially Brazilians! We have parties and spoil our babies and we show them off to everyone. You go to the store and everyone kisses your baby and hugs him.... we just love babies”

(Low C-class, 39 years old)

“All girls grow up to be mothers...it is what we do...if a woman doesn’t want to be a mother?...I don’t know I think she is a bad person and a bad woman...it is her job”

(High C-class, 18 years old)

Interviewees consistently referred to Brazilian women as being destined to become mothers.

When asked if motherhood was a choice, all respondents said no, it was a form of destiny. It was felt that women could only reach the apex of womanhood by achieving motherhood. Women
explained that this expectation has been placed on them since birth and is reinforced by their friends, family, and husbands.

“You can plan your life, but it will never happen as you think. You will become a mother and wife...it is just a matter of time”

(Low C-class, 19 years old)

“All girls want to be mothers. Girls grow up with the little dolls and learn to be a mother by pretending the doll is her baby. Girls grow up and take care of the cousins and siblings and know they will become a mother...I think we all grow up knowing we will be mothers and we all are excited.”

(High C-class, 19 years old)

Distrust in Contraceptives

To attempt to postpone a pregnancy seemed nonsensical to many interviewees as they believed becoming pregnant was out of their control. This lack of control was partially attributed to their distrust in contraceptives. None of the women interviewed felt condoms or birth control pills were trustworthy methods to avoid pregnancy. All women interviewed recalled an anecdote in which a friend’s contraceptive method failed, therefore creating the notion that contraceptives were consistently ineffective. Interviewees communicated feeling uneducated about contraceptives yet believing these anecdotes provided enough information for them to make their
reproductive decisions. None of the participants had received sex education in school nor received information about family planning from their PHUs.

“I don’t know about the pill, so I am scared to use it. My friends told me it hurts your stomach and can make you fat, so I don’t want to try it...so I just use condoms”

(Low C-class, 18 years old)

“All of my friends got pregnant using condoms...so why use them?”

(High C-class, 26 years old)

Women associated “heavenly intervention” as an explanation for phenomena such as a condom breaking, birth control pills not working, or a woman becoming unintentionally pregnant. Across interviews, it was suggested that because of the strength of heavenly intervention it was illogical for women to attempt family planning.

“I was using condoms and I still became pregnant with my daughter. It happened because God wanted me to become pregnant and wanted me to have a child.”

(High C-class, 24 years old)

“Why should I plan a future [pregnancy] when [God] has already decided for me?”

(Low C-class, 21 years old)
Women’s Age

The recommendation to postpone pregnancy due to the ZIKV crisis was moreover believed to be unrealistic because women felt trapped in a reproductive timeline. Interviewees associated the end of a woman’s reproductive timeline with difficulty conceiving, health issues during pregnancy, problematic deliveries, and miscarriages. Late-age pregnancies were additionally assumed to be perceived as selfish because as it could possibly harm the fetus or limit the partner’s opportunities for fatherhood. Interviewees associated these factors with familial, peer, and partner pressure to marry and conceive early to allow for multiple children, healthier pregnancies, and easier family management.

“My family always reminds me that I am already 32 and I need to have children because the older I am the more difficult it is…they all say ‘You need to be a mom so you’re not just a tia’ (laughs)...here in Brazil if you have no children and you are just an aunt people feel sad for you....all women need children.”

(High C-class, 32 years old)

“I am getting old and I need to get married and have children. My parents tell me they want grandchildren and my friends already have children and I am the last one...everyone is nervous about me not making a family...it is a lot of stress...”

(Low C-class, 26 years old)
When asked specifically about ZIKV, all women agreed that ZIKV was not enough reason to postpone pregnancy. It was explained that having children before the end of one’s fertility timeline was perceived as safer than waiting until a later time. It should be noted that interviews were conducted at a time of low ZIKV prevalence within the community.

“You do not know if you will get Zika...so why worry about the pregnancy? Live your life and create a family and you can worry about Zika IF it happens”

(Low C-class, 38 years old)

“How can I wait? Isn’t it better to have a child now so I can be healthier to beat Zika...than to wait and be old and struggle to beat Zika?...Women can’t wait forever...the older they are the more difficult it is...that is not good for the mother or baby....no women should not listen to the government...”

(High C-class, 35 years old)

II. Reasons to Control Fertility

A. Future Aspirations

Across interviews, participants felt a lack of control over their reproductive health – yet the strength of this control was dependent upon their socioeconomic class. In this study those who identified as High C-class felt somewhat able and willing to postpone childbearing if they aspired to higher education, increased income, or career growth. Women in this group believed
that these aspirations were important to achieve prior to childbearing as establishing a career, earning a steady income, and having a permanent partner would ensure a positive future.

“I do not want children right now...and I do not want a boyfriend...I need to finish school and get a good job first. My parents tell me education then money then husband and then children....it is so a family is easier, and the children will have a good life...”

(High C-class, 19 years old)

“I want to study and have a good job...I don’t want to have a baby... I need to have a good job and money first. Once you have a child you have to stop everything. Stop school, stop working. stop everything.... then your life is stopped”

(High C-class, 18 years old)

Many women of the Low C-class felt achieving higher education or careers were not possible for them, whereas childbearing was an inescapable reality. Women in this group felt educational, monetary, and occupational aspirations were unachievable, dissuading their willingness to attempt to postpone childbearing. Within this group, obtaining higher education was believed to be rare while teenage pregnancy was identified as very common.

“I had to stop school because I was pregnant and that was normal. I wasn’t going to study more or have a fancy job...my future is to be a mother so here I am (laughs)”

(Low C-class, 19 years old)

“I was pregnant in school and had to stop...but it is OK because I could not have afforded university...so I just started my family early...”
As other studies have noted, women felt a varying lack of confidence over their reproductive intentions due to the varying abilities, opportunities, and perceptions produced by differing socioeconomic classes (Marteleto, Weitzman, Coutinho, & Valongueiro Alves, 2018). Even within the often homogenized “middle class” it is demonstrated that there exist differences in opportunities, ambitions, and expectation caused by the disparities of affluence encompassed within the C-class.

B. Monetary Considerations

Interviewees were asked under what circumstances women should avoid becoming pregnant. All women indicated financial constraints as a major determinant in their willingness to have children. Women felt childrearing was incredibly expensive, demanding substantial, consistent, and long-term financing. Respondents believed children should not only be provided with food, toys, clothes, and education – but the highest quality possible. Interviewees were adamant in explaining that how many children a woman has should reflect how many children she can economically support with a “quality” life. Many women explained that having the best brands, education, technology, and clothes created a status symbol in Brazil and could open gateways for the children to have a good life.

“A mother has to provide for the child...and children are expensive! You need to have the best things for him and pay for education and pay for good brands or people will judge him and judge you as his mother...it is very expensive...”

(High C-class, 37 years old)
“Children take all the money! You need to make sure they have a good future so that means buying them good things...always having a lot of food... making them look good, paying for education....and the children stay in the house until they are old...so you need money for a long time.”

(High C-class, 30 years old)

Respondents associated a “good mother” with one who prioritizes the quality of their child’s life. Having four or more children was perceived negatively by most respondents as it was believed to reflect the actions of a selfish, uneducated, or sexually promiscuous woman. A high number of children was perceived unfavorably as it suggested each child would be given less attention, items, and financial resources, therefore diminishing their quality of life. An underlying trend in responses was that poorer women were consistently associated with being “uneducated”, “selfish”, or in some way “less fit” mothers than wealthier women. An example of this, is that respondents consistently believed that poorer women often have too many children. It is recommended that healthcare providers, risk communication, and communities be made sensitive to this stigma and deterred from admonishing women who may be pregnant during a ZIKV outbreak.

DISCUSSION

This study has three major conclusions: (1) women in our sample were not, and are not, postponing pregnancy due to ZIKV, (2) there exist numerous barriers to pregnancy prevention, and (3) not unexpectedly, socioeconomic class is associated with women’s fertility decision-making. Due to being perceived as undesired and unfeasible, women were not postponing
pregnancy because of ZIKV. Unfeasibility was associated with barriers such as: inability to have family planning conversations with partners or healthcare providers, women not feeling in control of conception, a distrust of contraceptives, and religious ideologies. Women reported feeling compelled to adhere to their family’s, friends’, partner’s wishes as it pertained to family size and time of pregnancy. Additionally, women reported feeling the need to become pregnant or have children to conform to social expectations. The cultural context in which the ZIKV epidemic unfolded cannot be ignored when assessing the appropriateness of recommendations made. Social norms, gender relations, societal expectations, communication styles, and conceptualization of behaviors all factor into women’s agency, desire, and ability to become pregnant or avoid pregnancy.

Several other qualitative studies rooted in Brazil have sought to understand women’s reproductive and family planning intentions, behaviors, beliefs, and barriers during the ZIKV outbreak (Arias, Tristan-Cheever, Furtado & Siqueira, 2019; Center for Reproductive Justice, 2018; Diniz, 2016; Linde & Siqueira, 2018; Marteleto, Weitzman, Coutinho, & Valongueiro Alves, 2018; Sousa, Mendes, Mufato, & Queiros, 2018). This study supports other evidence that during the time of ZIKV reproductive decisions continue to be tightly bound by sociocultural norms, attitudes, and practices (Arias, Tristan-Cheever, Furtado & Siqueira, 2019; Diniz, 2016; Sousa, Mendes, Mufato, & Queiros, 2018). This study additionally supports evidence that there continues to be limited access to reproductive health information, a full range of contraceptive services, adequately trained healthcare personnel, and unequal power dynamics within intimate relationships which all create barriers for women to access and use contraceptive information and methods during the ZIKV epidemic (Baum, 2016; Borges 2018; Center for Reproductive Justice, 2018; Duarte, 2016). These findings additionally support studies which have noted
Brazilian public health authorities’ lackluster attempts to enhance family planning services, reproductive health education, access to contraceptives, or reproductive health counseling services during the ZIKV epidemic to aid women to adhere to the recommendation to avoid pregnancy (Brito, 2016; Diniz, 2016; Wurth, 2017).

**Stratified Reproduction**

This study found the role of socioeconomic class to be associated with women’s fertility decision-making. This study aligns with the ideas of stratified reproduction as it found that respondents’ perception of, and willingness to engage in, delaying pregnancy was influenced by socioeconomic class and adherence to traditional gender norms. In this study, women’s self-identified class was associated with contraceptive options and their local meanings, fertility decision-making power, and potential life trajectories. Although there was a unanimous acceptance of the inevitability of becoming mothers, this came with the caveat that there exist reasons to postpone pregnancy to achieve higher education, a better career, and increased income. High C-class women felt able to finish their education and achieve an optimal career therefore motivating them to postpone pregnancy. Low C-class women reported feeling a lack of control and low self-efficacy to change the trajectory of their lives, assuming it would include early and multiple pregnancies, low education, low level occupation, and inconsistent partners – therefore their willingness to engage in pregnancy prevention was low.
CONCLUSIONS

To promote pregnancy postponement as a response to ZIKV does not consider the underlying context of women’s reproductive agency within Brazil. There exist divided fertility patterns in Brazil caused by growing divides in socioeconomic class, even within the “middle class”. Such a recommendation ignores gaps in reproductive agency and defies social norms - making it not only unrealistic but counter-cultural. A national call to modify fertility decisions cannot be adhered to until there is more equitable access to and education for family planning for the poorest women and families. To not do so makes the health recommendations a washing of the authorities’ hands, cleaning them of the responsibility for children born affected by ZIKV or other arboviruses.

As the risk of another cycle of ZIKV nears, health authorities are encouraged to revise their approach to prevention. To simply advise the delaying of pregnancies – or the recommendations about screening and repellent - cannot be seen as fulfilling the requirements for public health communication. More attention, support, and education need to be directed at women and their partners to enable them to engage in autonomous fertility decision-making. Decades of successful family planning promotion have laid out the necessary elements of campaigns to reduce or postpone pregnancies and shown the careful pathways to successful mosquito and arbovirus containment. A new epidemic is no excuse to forget the hard-won lessons of a century of public health promotion. A ZIKV epidemic control program, or the next arbovirus epidemic, needs to be developed, targeted and delivered using the principles of public health communication. The targets need to include partners of the women as well as the community, and effort need to be funded at levels that permit success, not symbolic contribution.
CHAPTER 6. Case Studies of Zika’s Forgotten Women (Manuscript 3)

BACKGROUND

The Zika virus (ZIKV) epidemic was of international concern during the height of its outbreak from 2015-2016. With the apparent decrease in cases, and decrease in microcephaly, media coverage decreased, along with programs and research efforts. Since the end of the global health emergency, relatively little attention has been paid to the experiences of women affected by ZIKV (Center for Reproductive Rights, 2018; Diniz, 2016; Wurth, 2017). Additionally, relatively few studies have explored women’s perceptions toward their children’s outcomes such as microcephaly and other birth defects (Albuquerque et al., 2019; Carvalho, 2018; Sá, 2017). Although the surge of ZIKV infections and related malformations have appeared to diminish, ZIKV is still endemic in many communities and fetal effects continue to occur. For many women whose pregnancies were infected with the virus, they and their children continue to experience the negative outcomes of the disease. This paper presents case studies of women who continue to be affected by ZIKV. We hope the paper acts as a megaphone for women to voice their perceptions of experiences with childbirth, child-rearing, fertility decision-making, and ZIKV.

Zika Virus (ZIKV)

ZIKV is a vector-borne flavivirus transmitted primarily via *Aedes aegypti* mosquitoes, perinatally, or through sexual contact between partners. Symptomatic ZIKV cases typically present with generic flu symptoms such as a red skin rash, fever, muscle pain, joint pain, headache, and malaise – yet most cases (80-90%) manifest as asymptomatic (World Health Organization [WHO], 2018a; Centers for Disease Control and Prevention [CDC] 2018a). Asymptomatic cases can be problematic, as patients may not seek testing or medical care.
Asymptomatic cases can also lead to unknown sexual or vertical transmission of ZIKV. Possible additional challenges for women infected with ZIKV include infertility, pain during pregnancy, miscarriage, stillbirth, and perinatal death (WHO, 2018a; CDC, 2018a).

*Congenital Zika Syndrome (CZS)*

Adverse birth outcomes associated with ZIKV became grouped under the name Congenital Zika Syndrome (CZS), to encompass the various consequences and outcomes that may appear as the child develops. Possible outcomes include: newborns born with smaller than expected head size (microcephaly), issues with brain development (cognitive inabilities), feeding problems (difficulty swallowing), hearing loss (deafness), seizures, vision problems (blindness), issues with joint movement (contractures), arthrogryposis, and difficulty moving due to stiff muscles (CDC, 2018b). It should be noted that emotional trauma, depression, and anxiety for the mother is often a secondary product of the ZIKV or CZS outcomes (Kotzky et al., 2019; Williams et al., 2019).

The most noteworthy outcome of ZIKV is microcephaly in newborns exposed to ZIKV in utero. Microcephaly is not a new congenital defect as it is often associated with the infectious agents of STORCH - syphilis, toxoplasmosis, other infections such as HIV, varicella, parvovirus B19, rubella, cytomegalovirus, and herpes virus (Neu, Duchon, & Zachariah, 2015). Microcephaly has also been attributed to interrupted blood supply to the baby’s brain during development (WHO, 2018b). Additional research utilizing mice models found that maternal protein malnutrition may increase a fetus’ susceptibility to CZS (Barbeito-Andrés et.al, 2020).

To date, there have been more than 3,000 children (over 80% of global CZS cases) born in Brazil
with confirmed cases of microcephaly and other complications of CZS (Pan American Health Organization [PAHO], 2018; Ministério da Saúde, 2019). These numbers are likely an underreporting of the true extent of the health issue as it does not represent the probable cases, cases still waiting classification, or the cases which have been lost to follow-up after birth. As many birth defects may not appear until months or years into development, it is assumed there are numerous cases lost to follow up.

**CZS Care**

CZS presents with disabling outcomes for both children and caregivers. Public health agencies such as WHO, PAHO, and the CDC recommend children born with CZS be referred to a long list of specialists: infectious disease doctor, neurologist, ophthalmologist, clinical geneticist, endocrinologist, pulmonologist, otolaryngologist, lactation specialist, nutritionist, gastroenterologist, speech therapist, occupational therapist, orthopedist, psychiatrist, physical therapist, and a physical rehabilitation specialists (CDC, 2018b; WHO, 2018b). In Brazil, it is recommended that children with CZS from ages 0-3 be referred for early stimulation programs offered through the public health system (SUS). These programs work to provide specialized auditory, visual, motor, cognitive, communicative, and manual stimulation services (Ministério da Saúde 2016; Ministério da Saúde 2017). Reports from the Brazilian Ministry of Health have documented that mothers often face barriers in accessing these services (Ministério da Saúde, 2017; Ministério da Saúde, 2018). For example, according to a national survey by the Brazilian Ministry of Health’s Department of Health Surveillance, only 42% of children with CZS were receiving early stimulation (Ministério da Saúde, 2017; Pereira, 2017).
The Mothers

As the epidemic began to unfold, the Brazilian Ministry of Health recommended that women avoid pregnancy as a way of preventing births associated with CZS. The recommendation must have assumed women have control over conception, but this is challenged by the 55% unintended pregnancy rate reported in Brazil (Schuck-Paim, Lopez, Simonsen, & Alonso, 2016). These public health authorities must have assumed additionally that women would be willing to adhere to this advice. This fails to acknowledge the sociocultural context of gender norms and sexuality, family and social dynamics, and religious and other fertility-linked beliefs in which women live. Recommendations made by public health authorities urged women to seek reproductive counseling from healthcare providers, yet providers were not trained and in general did not offer these services (Albuquerque, 2018; Wurth, 2017). No matter the potential outcome of interventions, there is now a new cohort of women raising children with CZS whose experiences need to be explored to understand the long-term effects of the disease and the adequacy of the response.

METHODS

This study utilized a case study approach, grounded in ethnographic techniques of extended, multiple interviews. The purpose of this research was to better understand the experiences of women who had adverse pregnancies associated with ZIKV, as well as their experiences raising children with CZS. This study is not meant to highlight unique cases of the
phenomena – not the worst nor the best of the mothers affected by ZIKV- but cases which best demonstrate the patterns of shared experiences described by the women in the study.

Case Study Approach

This study was nested in a larger cohort study “Zika em Fortaleza: respostas de uma coorte de mulheres entre 15 e 39 anos (ZIF)” (Zika in Fortaleza: responses of a cohort of women 15-39 years old). The nested nature of the study provided a base to build on and helped maximize the time in the field. This study was done in partnership with the ZIF study team, which is led by principle investigator, Dr. Ligia Kerr, MD, MPH, PhD. and co-PI Dr. Carl Kendall, MA, PhD. This research collaborative included a team of doctoral students, anthropologists, nurses, physicians, epidemiologists, biostatisticians and lab technicians and was housed at the Federal University of Ceará (UFC) in Fortaleza, Brazil. This collaboration served as an opportunity for sharing information, training graduate students, and brainstorming approaches to investigating the effects of the epidemic.

Between June 30, 2018-August 25, 2018 formative research took place in the form of attending ZIF team meetings, visiting public health units (PHUs) where the study was being conducted, collaboratively planning data collection, piloting instruments, and conducting community observations. Data collection took place from December 16, 2018 to January 25, 2019. Recruitment and data collection for the RAA took place in two public health units (PHUs) in Fortaleza: Posto de Saúde Graciliano Muniz and Posto Unidade de Saúde Escola Casemiro

---

8The ZIF cohort study received IRB approval, granted by the Federal University of Ceará (FWA # IRB00004330). IRB approval was for this nested study was first approved as an addition to the cohort study and was then granted approval by Tulane IRB on December 16th, 2018 (IRB# 2018-1606).
Jose de Lima Filho. Within Brazil’s unified healthcare system, *Sistema Único de Saúde* [SUS], the PHU is the basic health service that provides primary medical care, health education, medications, and vaccinations. The two selected PHUs are the primary providers for the two communities in Fortaleza and are directly supervised by faculty at UFC.

The first phase of the study was a Rapid Anthropological Assessment (RAA) that explored an array of women’s perceptions of ZIKV, fertility decision-making during the ZIKV crisis, and their experiences with ZIKV and CZS. This study collected data utilizing a Rapid Anthropological Assessment (RAA). The RAA encompasses semi-structured, in-depth interviews, free listing, scenarios, open-ended questions, and close-ended questions. These approaches are triangulated with informal conversations and observations in the study setting (Kendall et al., 2005; Scrimshaw, Carballo, Ramos, & Blair, 1991). The RAA designed for this study used scenarios, free lists, case frame questions, and a mix of qualitative and quantitative questions. Women aged 18-39 were recruited for the RAA and each completed an interview at one of the two designated PHUs. All participants were explained the study in detail, were walked through a confidentiality statement, and completed the informed consent process. The PI of this study conducted all interviews. Interviewees declined audio recording. This was a foreseen possibility due to the sensitive nature of the topics such as reproductive health and sexual practices. Extensive notes were taken during the interview and the PI followed up via phone call 24-72 hours after their initial interview to verify the content of the notes and to ensure the data sufficiently represented the interview. The RAA interviews lasted approximately 30-120 minutes. There were 35 women who participated in the RAA. Findings from the RAA were used to inform the design and delivery of questions for the case studies.

*Selection of Cases*
Participants for the cases were identified from the RAA study sample. Women who participated in the RAA, were eager to talk about the topic, were comfortable with the interviewer, and were willing to continue interviews, were asked to volunteer as a case study. No participants declined. Further participation in the case studies was aimed at delving further into women’s experiences with fertility, pregnancy, and childrearing outcomes amidst the ZIKV and CZS outbreak. Cases were selected to represent a spectrum of fertility, pregnancy, and childrearing experiences of women affected by ZIKV. A case was selected for each of the following situations: an abortion, a miscarriage, a current pregnancy, a woman of higher socioeconomic status who had a child with CZS, and a woman of lower socioeconomic status who had a child with CZS. We made no effort to identify the most extreme clinical conditions or outcomes, but rather focus on women whose experiences were more like other women in the same situation. The final cases were chosen because the stories, experiences, and perceptions of the women coincided with those of women in similar situations - therefore allowing these cases to act as a mechanism to ground themes into one person’s story. When developing the case study for the woman who had an abortion, it turned out that her situation was truly exceptional and did not fit the narratives of other case studies. The analysis of this case study requires a more complete discussion of issues related to abortion, and not solely to ZIKV. We have used that case in an accompanying paper on abortion and ZIKV.

Subsequent follow-up visits with mothers selected for the case studies took place in the participants’ home or during additional health care visits. Each case study included a series of five to seven in-depth interviews that were paired with observations and informal interviews with the woman’s family and friends. Interviews lasted approximately 70 to 200 minutes. Women preferred to not record interviews therefore extensive notes were taken during the interview to
serve as the basis for completed fairnotes prepared after the interview. All interview notes and completed narratives were shared with participants to verify accuracy. Pseudonyms are used to preserve the privacy of the interviewees. All participants expressed having enjoyed the interview process. As a gift of gratitude, all case study participants were given a handwritten booklet describing the story they shared with the PI during the study.

**Observations and Informal Interviews**

A range of informal observations and interviews contributed substantially to this paper, as is inevitable with an ethnographic approach. Observations included: health education for ZIKV in clinics, radio, or TV; patient-provider interactions, clinic organization and environment; community characteristics and home hygiene; notes taken in pharmacies, clinics and supermarkets pertained to types of resources provided, availability of services within the facilities, amount and types of individuals in the clinics, waiting times in the clinics, general behaviors of individuals inside the clinic, location within the community, physical features, and assets; and media such as music, television, radio, and social media (Facebook, Instagram, and Twitter) to understand how ZIKV and individuals associated with ZIKV were being represented and discussed. Content of the media was noted, as well as the creator of the media source, trends in the timing of media, and how the media was shared or perceived.

Informal, informational conversations included discussions with community members as well as people within the priority population. Informants included: mothers of interviewees, boyfriends, husbands, siblings, friends, cousins, nurses, physicians, pharmacists, psychiatrists, public health professionals, communication specialists, and members of the Ministry of Health.
These informal interviews were used to help the researcher better understand the setting and the experiences of the women included in these case studies.

**Analysis**

Fieldnotes were collected including notes from interviews, observations, and feedback from the ZIF study team. Completed interview guides and fieldnotes were compiled into fairnotes. Fairnotes are documents which include observations, fieldnotes, informal discussions with community members, and conversations among members of the research team. The purpose of generating fairnotes is to contextualize data and organize it into a polished and shareable document that best reflects the interview conducted (Halcomb & Davidson, 2006; Hill, 2003; Kendall et al., 2005). The effort to transform interview notes and observations into fairnotes contextualize the interview and create a permanent record that can be revisited long after audio recordings have either been destroyed by IRB mandate or become otherwise unavailable. The act of creating fairnotes is itself analytical, since fairnotes are organized in the research guide to provide direct answers to research questions.

An iterative process of fairnote development took place as notes were continuously shared with participants to check for accuracy in representation, interpretation, and meaning. These case studies were additionally assessed following Yin’s techniques of pattern matching, explanation building, and time-series analysis (Yin, 2002) to deduce salient themes. Patterns across women’s experiences were compared, explanations as to how women conceptualize motherhood and ZIKV were explored, and a time-series approach was taken to understand how women’s experiences compare from generation to generation as well as from the epidemic stage.
of ZIKV to the current time of endemic ZIKV. Fairnotes were reviewed then uploaded into NVivo 12 Pro software where responses were coded, narrowed into categories, and themes were identified highlighting key concepts used to address the research questions.

FINDINGS

CASE STUDY 1: MISCARRIAGE

Juliana is a 34-year-old female born and raised in Fortaleza, Brazil. She and her husband have been married for four years and together for over a decade. The couple lives on the third floor of the apartment complex where Juliana’s parents live on the first floor. Juliana completed some college education yet neither partner finished college. Both she and her husband are employed at the local airport and self-identify as high middle class. Juliana and her husband have no children, but in 2016 Juliana was pregnant for the first time and elated. She was 31 years old at the time and had been married to her husband for over a year. She explained:

“I was pregnant FINALLY! Finally, pregnant and finally happy! We always wanted children and wanted to get married to have children. As soon as we were married, we wanted a child...we tried and tried and finally after a year I was pregnant, and my husband cried when I told him. Everybody cried we were so happy...my mother, my father, my cousins, my friends. Everyone was so happy. I was so happy to finally be pregnant because I was already past 30...everyone knows pregnancy is more difficult after 30...”

During the rainy season of 2016, Juliana was about three months pregnant. She was feverish and vomiting and was unsure if this was morning sickness, pregnancy woes, or perhaps dengue.
Juliana explained she didn’t think it was worth worrying about and never thought it would be Zika.

“*I was vomiting and hot all over my body but that could be just pregnancy so I thought maybe I will wait and see if it passes. I was drinking juice and eating beans and meat which was good and healthy. My husband was worried and drove me to the clinic because he worries about everything *laugh*. When I was there, I told the nurse and doctor that I think I had a fever. They gave me a needle and a bag [IV] that my husband had to hold while they took blood from my arm. I wanted to go home but they told me to wait. They said it might be Zika and I didn’t think it was possible because that was in Pernambuco and was for the favelas and pobreza…. not me…you know I was clean, and my house was clean, and I was healthy so why would it be Zika?”*

Juliana described how she truly thought Zika was not possible. Although it was at the heart of the ZIKV crisis, she thought she was removed from the problem. Juliana explained how she hadn’t seen any Zika cases in her neighborhood, none of her friends had Zika, and all she saw on TV were images of poor women in places like Bahia and Pernambuco. Juliana confessed she had been doubtful if ZIKV was real:

“*Nobody really believed Zika virus at first. A new virus with the same mosquito? So strange! And this virus only hurts women? Why is it dengue but different? How is this happening? Brazilians love political conspiracies and so we all thought it was the spraying [pesticides] or the government polluted the water or maybe these were things uneducated women were doing...drinking...smoking...you know things that hurt babies already...*”
The medical staff told Juliana she was ill because she had ZIKV. Juliana remembered reacting with a combination of disbelief and anger. She recalled the indelicate nature of the delivery of this information as well as the unhelpful nature of this result. Juliana was told there was no cure, treatment, or way to mitigate the effects of the virus. This news left her and her husband with tremendous stress and a deep feeling of doom.

“They just said ‘you have Zika probably’. And I remember thinking... ‘why do they say probably?’ I asked and the doctor said that the test wasn’t completely accurate, and I cried I was so angry. Why tell me I am with Zika if I am not? Why worry me? Then they tell me that there is nothing I can do! NOTHING! So, I am crying, my husband is crying, and I am sitting there thinking this stress will kill us all.... Stress you know is bad for a pregnancy and can hurt the mother, the baby, and maybe the father....I am so mad they told me about Zika with nothing to help. They say maybe Zika and do nothing...it was terrible...just waiting and praying and crying...Nobody gave me information about how to protect my baby, nobody was helpful, and I felt like everybody was whispering about me being a dirty woman with Zika...”

Juliana began to cry as she explained the timeline of her pregnancy. Juliana remembered the pregnancy as difficult – she was unable to sleep, she was nauseous the entire pregnancy, she was unable to eat, and had blood spotting throughout the pregnancy. Juliana attributed this rough pregnancy to the stress she experienced after being told she had ZIKV. Her husband explained becoming depressed as he felt helpless watching his wife suffer. There were good days and bad days of the pregnancy, but the unknown nature of the disease’s course would not let the couple rest. Juliana did not attend prenatal care visits because she felt the healthcare system could do nothing to help her. At seven months Juliana had a miscarriage:
“I woke up one day and she [the fetus] was still sleeping... I waited all day and she did not move. I began to bleed, and my husband and I just went to the hospital.... we said nothing because we knew. We just cried and said nothing... I do not want to talk about the procedure because I still have nightmares... when you deliver a baby you want to hear it scream, not the silence. I just remember the whole day was silent and filled with crying. When I woke up my husband was there crying, and the doctor told me my baby was gone. I just cried and cried and asked why this was happening... the doctor said it was the Zika probably.... I just cried and cried and cried...”

After the miscarriage, Juliana became extremely depressed. Juliana’s sisters told me she would not leave her bed and would not use her phone. She was “a zombie” for weeks. Juliana’s parents described her experience hurting all of them, that it was a miscarriage of the family, not just of Juliana. Juliana and her husband became distant after the miscarriage, intensifying their pain.

Juliana was pregnant for a second time when I interviewed her. She was past the three-month mark and already showing. Her husband was the first to tell me because he was too excited to keep the secret. When asked why it was a secret, the family explained they did not want to jinx the blessing and were trying to be cautious with this pregnancy. When asked what was different about this pregnancy, Juliana explained:

“After a while my husband convinced me it was time to try again. I am now pregnant, and we are all so happy, but I am very nervous. After the miscarriage I found information online about Zika and I read everything I can about it. The doctor says I won’t get it again, but I am not trusting anybody. I am using repellent and condoms and eating healthy. My mother cleans my house and my family is always bringing me food. I want to
be healthy, so I am relaxing a lot because stress is dangerous…I learned that from last time.”

Juliana believed she had done “everything right” in her last pregnancy but ZIKV had taken her child. Miscarriages are common in Brazil, but the cause of the miscarriage being ZIKV scared her. She believed that ZIKV was an uncontrollable disease where “even if you do everything right” it was possible to be infected and suffer incredible consequences. Juliana was able to find other women who experienced miscarriages and stillbirths due to ZIKV. She explained that finding these women helped her to feel less alone and less like a bad mother.

“I thought I was a bad person…or a bad woman…because I was a bad mother. I prayed a lot to God for help…I still pray a lot because I am scared. It was a long time until I was pregnant…and then finally I am, and I cannot have a child? Maybe it is not me, but it hurts. I want to be a mother so much and I am worried that I am only getting older. What if I do not have a child? I might die from depression and embarrassment…oh how people will judge me and pity me…I do not want that”

Juliana’s experiences were echoed by several other respondents. The concept of miscarriage representing a failure of the woman was a common concept in the community. It is unclear how many miscarriages or stillbirths were caused by ZIKV, yet it was perceived by Juliana and several other respondents to be a common occurrence. ZIKV was dangerous to a pregnant woman because it was a disease whose path was unknown. Women interviewed felt there was no control over the impact the disease would have – this unknown outcome, lack of control, and sense of helplessness were described as the worst parts of ZIKV.
When asked about the impact ZIKV has had on her life, Juliana explained that it changed her. Having the miscarriage was a radical event that created rifts in social interactions and left Juliana with self-doubt, depression, and confusion. ZIKV had “robbed her” of what she wanted most in the world, to be a mother. This lack of identity and gap in her life left her feeling aimless and confused as to how to move on. Juliana believed ZIKV had taken the happiness out of her second pregnancy as well. She felt shaken to the core and now doubted her ability to protect her baby and be a good mother. Juliana lamented as she discussed feeling as if her stress, fear, and depression were causing a divide between her and her social network. She also worried that these feelings would negatively impact her current pregnancy and once again leave her childless. This case demonstrates that although ZIKV infection may not have led to a case of CZS, it has left its mark on those mothers who lost a child, their identity, and their confidence.

CASE STUDY 2: PREGNANCY NOW

Elaine is a 21-year-old woman from Fortaleza, Brazil. Elaine completed a high school education, was not interested in a college education, and earned a living working at the local mall. Elaine had a boyfriend of four years and was five months pregnant at the time of the interviews. Elaine explained her perceptions of her pregnancy:

“Of course, I am excited! I was not trying to be pregnant, but it is not up to me...God decides when it is time for a woman to be pregnant. So, we will see what He has planned for this pregnancy and this baby...I did not plan for this baby, but I think that is common, no? I think all women are surprised when they are pregnant and maybe nobody has a baby when they plan to. But once it happens, it happens, there is nothing you can do but
be excited about motherhood... I hope it is a boy because that will make my boyfriend happy. My boyfriend is happy sometimes about the pregnancy and not happy sometimes about the pregnancy...but our families are very happy and excited.

Unintended pregnancy was perceived as a common occurrence within Elaine’s community and social network. Pregnancy was frequently perceived as an “unplannable” religious intervention. Questions were asked about her perceptions of ZIKV, the scope of ZIKV within her community, if she was worried about ZIKV, if there were any preventative behaviors she was engaged in, and if she was doing anything special or different to ensure a healthy pregnancy.

“Zika is gone, I think? I do not see it on television, and I do not see people around me sick from Zika...people are always sick but with dengue and chikungunya...I think Zika is not a problem for me because I am just cleaning my house and eating well. Women who clean their houses do not get sick...if you have a dirty house you get sick. To have a good pregnancy a woman needs a lot of rest and a lot of good food like juice and beans and meat. I walk a lot too; my cousins tell me that walking a lot helps the baby to be strong and helps me not to get too fat *laughs*.”

Future interviews showed that Elaine believed she had no control over ZIKV nor mosquitos. She explained that even if she meticulously cleaned her house, used repellent, or purchased a mosquito net, the mosquito would appear and bite her. This lack of ability to control the mosquito was frustrating to her because she felt she was unable to become ill without judgement from her peers. Her family echoed this sentiment, explaining that if people get sick, they are often blamed for being uneducated, unable to keep a clean home, dirty, or unhygienic.
“You know...I think I fear getting Zika because it is over so nobody would believe me. They will think ‘why did she get sick, what did she do wrong?’...and that is not fair. I can do everything correctly and still get sick. But people judge you. So, if I am sick with Zika then I have a dirty house, or if my baby has a birth problem then I did something wrong during the pregnancy...it is bad...it isn’t fair. My friends...my mother...everyone they say, ‘do not stress about Zika or about the pregnancy...if you’re a good woman it will be fine’...but how do I do that?”

Elaine explained that she was not given information from the health unit about ZIKV. She believed this was because the ZIKV crisis was over. Elaine felt that ZIKV was no longer an issue due to the lack of notices on the news and in the health clinics. Elaine felt it had been at least a year since someone in her community had been infected with ZIKV. This low risk perception led Elaine to believe there was no need to try to prevent ZIKV. Elaine also felt that her money would be better used on purchasing items for the child as opposed to ZIKV prevention.

Elaine felt that worrying about mosquitoes and mosquito-based diseases was futile. Additionally, it was believed that this anxiety would be harmful to the pregnancy. Stress was toxic, something that could harm both the mother and the fetus. Elaine’s boyfriend, family, and friends all explained that being stressed was dangerous to a woman, therefore it was important for women to feel supported during their pregnancy to help mitigate stress.

“Stress can kill you and can hurt the baby. Women who worry a lot cannot sleep, cannot eat, and cannot relax...this is what hurts the pregnancy. I know I need to sleep a lot and eat good food, so the baby grows. If I am panicked then the baby cannot grow and the
pregnancy will hurt more...so no I cannot worry about mosquitos...it is dangerous to get a bite...but it is dangerous to worry about the bite too, you know?"

This concept of stress was consistent throughout the interviews. It was believed unnecessary to allocate stress to ZIKV, yet stress could be allocated to issues such as companionship, money, and social standing. Elaine explained that her fears were rooted in abandonment and economic struggles. Elaine’s biggest fear was her boyfriend leaving her. This was feared because it would leave Elaine feeling rejected, unloved, and financially instable.

"I know I shouldn’t worry...but I do. I worry [my boyfriend] will leave me and I will have no money for me and the baby...sometimes men panic about being a father and leave...you know aborto paterno. But if he leaves, I will be lonely, and fat and I will not have money for the baby to have a good life...that is so sad...oh and what people will say?! If I am a mother without a boyfriend or husband...what a vagabunda...people love to say bad things about the evil woman who is pregnant with no man...she must be promiscuous...she must be a bad woman...”

When probed further as to this form of prejudice, Elaine explained it can severely impact a woman’s social standing. Other members of Elaine’s social network, other women interviewed, as well as community members all confirmed this as being a common occurrence. Elaine felt that this social risk was more serious than the risk imposed by ZIKV. She felt adhering to her boyfriend’s wishes was more important than protecting herself from ZIKV.

“'I am so scared of him leaving or maybe he will get mad at me. I am trying to be good and have a good baby because maybe if the baby has a problem like micro [microcephaly], he will blame me and leave. I think if the baby has a problem the man
will leave... maybe that is a reason to be afraid of Zika.... but you know it is the money too. Most of these things *gestures to a pile of baby toys and supplies* were presents from friends and family and I am so thankful because I could never buy all of this. You know it is the mother’s job to provide for her child and make sure the child has a good life of quality... the baby needs good toys to be happy and good clothes to look cute... it is very expensive to have children and parties for the children and the school for the children. When you are pregnant you panic because you need money and because once the baby arrives there is no time to find more money or another man or anything....”

Elaine’s case is meant to represent this new cohort of women becoming pregnant after the ZIKV epidemic. These women are not directed to allow a place for ZIKV in their lives. Women are not being instructed on ZIKV prevention, are not viewing constant news segments on ZIKV, and are not witnessing ZIKV cases within their communities. It was commonly perceived that ZIKV was no longer a threat and was not “worth” worrying about for women in Fortaleza. The stress that could be allocated to ZIKV was felt to be dangerous as it could negatively impact the mother and child’s health. Anxiety over ZIKV was additionally seen as futile as mosquitoes were assumed unavoidable, even with proper preventative measures. Pregnancy was a precarious time because male partners were assumed to be constantly tempted to abandon the woman, thus leaving her emotionally, socially, and economically disadvantaged. Here, and in other interviews, it was believed that ZIKV was dangerous as it could negatively impact this fragile relationship between partners if the woman were to lose the baby or the baby was born with health issues.
CASE STUDY 3: MICROCEPHALY (Low middle class)

Bianca is a 26-year-old mother of three – an 8-year-old, 5-year-old, and 2-year-old. Bianca has a boyfriend of ten years who is the father of all three children. Neither parent has a college degree and both work as cashiers. Bianca lives with her parents in their apartment. Bianca self-identifies as low middle class. Bianca’s newest child is a 2-year-old daughter born with microcephaly. Her daughter is small for her age, wearing clothes marked for children of 12-18 months. Her head is visibly smaller than her body and is covered by a pink hat with red hearts. Bianca believes it is best to always cover her head to avoid the gazes of onlookers. Bianca’s daughter was experiencing issues with sight, hearing, and swallowing.

In the second trimester of her pregnancy, Bianca remembered having a fever but did not seek healthcare. She felt the fever would pass and that it was common for pregnant women to get fevers. She had had fevers in her previous two pregnancies and assumed it was the same situation. Bianca was still working at the time of her fever and felt seeking healthcare at the local PHU would result in a loss of hours and therefore a loss of wages that she could not afford.

“I woke up in the middle of the night and I was hot all over…like I was on fire! But I thought ok this is just a fever, drink some water and go to sleep. I had a fever in my other pregnancies, so I figured it was normal…so I didn’t think anything was strange. And you know it wasn’t worth it to go to the clinic…I would have needed to miss work to wait there for the entire day and then what? They can’t do anything for you if you have a fever. They tell you to lay down and drink juice…I can do that without a nurse telling me to *laugh*…so I worked and in three days I was fine, no problem.”
Her daughter was born in 2016 at the height of the epidemic. Her daughter was born prematurely at 36 weeks and was immediately placed in the neonatal intensive care unit, Bianca was unable to see the baby until the next day. The doctor told her the baby had been born with microcephaly which is thought to be caused by ZIKV. Bianca remembered feeling panicked when the medical team interrogated her about her pregnancy before she was able to see her child. She recalled feeling frustrated when she asked them questions but received no answers:

“\textit{When they took her away, I knew something was wrong, so I cried and cried and cried and asked them to bring me my baby. Then the doctor came back and told me it was micro [microcephaly] and I panicked and cried.... I was crying and they kept asking me questions like ‘did you have Zika virus, did you have a fever, why didn’t you tell someone, what happened during your pregnancy’ and on and on...they acted like it was my fault and I was so upset I just wanted to see my baby I thought she was dead. Then they said I could see her, and I asked questions like ‘what do I do now? When can she come home? What services are there for her? How do I care for her?’ and nobody answered them...they just said ‘I don’t know, I don’t know’...”}

Bianca sobbed as she relived the stress, sorrow, and pain she felt in the first few weeks after the delivery. She had felt unsure of her daughter’s future and worried that her daughter would die. The medical team also seemed worried about the situation which only amplified Bianca’s anxiety. Bianca kissed her daughter on the head as she explained her determination to protect her child. Bianca spent the last two years reading as much as possible on ZIKV and watching all the videos she could find on the disease. She felt it was her obligation to learn about this disease to best help her daughter:
“I realized I needed to know what this Zika was...I have read everything; I have joined all the groups of mothers with children like my daughter. I have watched every news video. I am learning with the doctors so I can help more than the doctors...for example early stimulation is very important for my daughter and I cannot go to the doctor every day for it...so I learned about and I do it at home. I need to be the mother, the doctor, the nurse, the everything for her. It is a lot of work which is why I quit my job and now this is my job...”

Bianca expressed her disappointment in the healthcare she received and felt that the healthcare her daughter needed was too difficult to access consistently. Bianca felt unable to juggle constantly fetching prescriptions while organizing her daughter’s extensive list of appointments for early stimulation, health education, monitoring her daughter’s growth, and so on. Bianca did not have a car and found public transportation too unreliable to attend all the appointments. Other barriers to Bianca seeking healthcare included: a long wait for services, confusion about which prescriptions and services her daughter needed, extensive and expensive travel for appointments, and the judgement she felt from onlookers.

“I have so many appointments for her all the time. The doctors get so mad if I do not go to all the appointments, but they do not know! The buses here are always late or do not show up, are they going to give me a car? Then on the bus I have to see people staring at my daughter or worry about what they say and their judgement? Maybe they take a picture for Facebook!.... And I need an entire day to get to the appointment and wait and then the doctor cannot do anything for her but maybe measure her head again? That is stupid!...and I am doing all of this with my other children because what am I supposed to do, leave them at home? No, it is too much work with no results. I will get the medicine
because it is important, and I will do early stimulation at home...but it is impossible to see all the doctors and do all the things...

Bianca had quit her job due to the extensive amount of care and attention her daughter needed. Bianca felt the difference between her daughter and her other two children was immense, causing a lot of tension within her family. Bianca’s mother and boyfriend had comfortably acted as alternative caregivers for her first two children, allowing Bianca to continue working. Bianca believed her mother and boyfriend were not comfortable caring for her daughter with microcephaly:

“This baby is different, and everybody knows. She cries more and is more agitated all the time. It is very hard to comfort her and to calm her down...this is very difficult for me and my mother. We are used to knowing how to handle babies, but this one is so different that it is frustrating. I don’t think my mother likes to care for my daughter...she enjoyed caring for the first two children. My boyfriend is awful...he left me because the baby was always crying and he couldn’t sleep...he felt like he would hurt the baby because she was so fragile...the stress of the situation drove him away...this baby is a lot more work than any other baby...”

Bianca’s boyfriend said he left because the child had been born with microcephaly. Bianca’s family and friends agreed that her boyfriend had explicitly stated that the costs and fatigue caused by the newborn were reasons he felt he needed to leave. Friends of Bianca believed he always wanted to “be free” and saw this as an opportunity to leave. Interestingly Bianca and her network, although angered by his actions, believed his leaving to be normal.
“Men can leave if they want to…they see a difficult situation and they just run. Probably he always wanted to leave and thought this was a good opportunity…it is typical of men around here…they do not need to stay; they do not have the responsibility to stay… that is the mother’s job. You know the government forgets about us and the men do too...you cannot blame the men for something that even the government does! Forgetting about women and our babies is just what they do...”

Bianca was referring to the lack of commitment the government had to children born with microcephaly. At the time of her daughter’s birth in 2016, there was a lot of attention placed on children with microcephaly. Media outlets were full of stories of the government creating supportive programs for these children. Bianca recalled that in 2016 there had been copious interest in her daughter from doctors, nurses, researchers, scientists, and social activists. At that time Bianca had felt hopeful that there would be continued support for her daughter and microcephaly management. With the decline of cases, there was a national decline in interest and funding for ZIKV and CZS. Bianca felt the government and health system had abandoned her just as her boyfriend had.

“Everyone wanted to help my baby in 2016. Everyone wanted to help the Zika moms and Zika babies and I was happy. But now? Nobody cares! My baby is about to be three years old and then what? Everybody told me the services were until she was three years old? What about school? What about the rest of her life? Now that Zika is over nobody cares about us...nobody cares because we aren’t important anymore...”

Bianca felt guilty talking about her health as a priority. She felt that complaining about the difficulties of raising her child or lamenting over the toll it took on her mental wellbeing, was
selfish. After a few interviews, Bianca began to discuss how lonely and depressed she felt. Bianca explained feeling at fault for her child’s disability, like a bad mother and a bad woman because she had done this to her child. She also felt that she had been neglecting her other children as a result of her daughter needing constant attention. This was contributing to her feelings of being a bad mother. Bianca described feeling lost in trying to raise a child with a disability and anxious about her daughter’s position within the community.

“Nobody teaches you how to raise a child with a disability...maybe they talk about early stimulation...but nobody prepares you for the feeling of failure or the constant worry that she is going to die...You have to go to get all these different medications, and go to all the appointments, and you hope SUS covers it...but what about all that time to do that? And to travel with a screaming fussy baby with micro is so hard...it is so hard and take so much time...and I can’t leave the house without worrying about someone taking a picture of us or blessing us or giving us bad looks because they think she is no good...how am I supposed to do this? I pray a lot...”

Bianca expressed a lot of gratitude that her daughter was almost three years old despite the difficult path it has been. Bianca was proud of how beautiful her child was yet felt extreme anxiety when leaving the home – as she believed people around her felt uncomfortable when they saw the baby’s smaller head and heard her scream. Bianca explained that when she left the house with her daughter, she felt the need to cover her with blankets and hats so nobody would see her to ridicule her. Bianca believed her daughter was a fighter and had a long future ahead of her. This future was something Bianca thought about often – how her daughter would grow, if new disabilities would come to surface, if her daughter would be allowed to go to school, and so on. For Bianca, the most important thing was to make sure her daughter felt loved and supported
by those around her. Bianca did not want her child to be associated with ZIKV stigma forever. Bianca hoped for more resources, increased support, and subdued stigma for her daughter.

CASE STUDY 4: MICROCEPHALY (High middle class)

Maria is a 32-year-old, married, professional woman who self-identified as high middle class. She and her husband live on the third floor of an apartment complex. Both individuals had some college education and come from educated, middle-class families. They have been married for five years, and both sets of parents live within a five-mile radius of their home. The couple has one child – a three-year-old son who was diagnosed with CZS in the form of microcephaly and hearing loss.

Maria is calm as she explains that there was no fever during her pregnancy, no signs nor symptoms of ZIKV whatsoever. Maria insisted she had “extensive prenatal care” which included prenatal vitamins, monthly check-ups with nurses, physical activity, and plenty of healthy food. Throughout her pregnancy, Maria adhered to advice from her mother, mother-in-law, sisters, and friends. Maria explained that she felt confident during her pregnancy and excited to be a mother. Maria and her husband pooled their money to pay for a sonogram at about 25 weeks to see the sex of the baby. During the sonogram, the couple was shown their son’s cranial calcifications and was told of ZIKV. Maria recalls:

“My pregnancy was perfect; I had no problems at all...and then during the sonogram we were shocked. The doctor was shocked too and was nervous. I did not believe him. I thought he was making a mistake. He asked other doctors to look at it too. We cried and cried and cried when they told us it was probably microcephaly and Zika. I did not
believe him! My pregnancy was perfect! We were arguing that it couldn’t be that because I did not have a fever and because I had no mosquito bites on me…nobody believed us…they just shook their heads and said ‘sorry there is nothing to do but wait’….WAIT? FOR WHAT?!...it was a really hard time.”

Maria was livid as she recalled the physician not believing her when she explained she had not been sick. Likewise, she did not believe the doctors in their diagnosis. Maria explained that up until that point she thought she had been perfect during her pregnancy. She thought she behaved in all the right ways that would ensure a healthy pregnancy and child: praying, eating healthy foods, taking prenatal vitamins, rest, and exercise. Maria recalled this diagnosis making her depressed for the remainder of her pregnancy. She spoke of continuously feeling nervous, constantly having nightmares about the baby dying, and not being able to rest for the weeks concluding her pregnancy.

Maria reminisced about when the couple told the family about the baby’s situation and smiled as she recollected all the love and support, they were given by their friends and family. Family members helped purchase items for the baby. Her friends would visit her at home and help with the chores, cooking, and cleaning. Maria and her husband explained how blessed they felt to have such supportive people in their lives. Maria explained that even though she had all this support, she was constantly worrying about her son. She recalled feeling ‘obsessed’ about ZIKV and spending the remainder of the pregnancy reading about microcephaly and ZIKV. Waiting for the birth was torment for Maria as she felt helpless. Maria recalled the delivery as being very difficult with a long labor. Her baby was born healthy other than the microcephaly and some hearing loss. Maria felt very relieved:
“I was worried he would die or that I wouldn’t be able to hold him...I had so many nightmares that I wouldn’t be able to hold him. But afterwards I look and there he was crying and wiggling like a normal baby and I was so happy. We all cried – I cried, the nurses cried, the doctor cried, everyone was so happy he was alive. *Crying* I love my son so much I think my heart will explode sometimes. He is a happy baby and a quiet baby, and I am very lucky.... I know that it is our job as women to love our babies, but he makes it so easy. I love him so much and worry so much...”

In subsequent interviews, Maria explained that her son rarely sleeps, has difficulty eating, and screams constantly. She believed caring for her son was more difficult than other babies she has cared for, such as her sister’s children. Maria left her job to care for her child fulltime. This lack of income has been a challenge for the couple. The costs associated with the medications, early stimulation visits, and healthcare appointments contribute to the financial burden of childrearing. Maria felt fortunate that her family was near to help with the housework and that she had the financial means to access healthcare services, and higher quality goods for her child. She thought the quality of these goods and services maintained her child’s health:

“I know we are not rich, but we are not poor and that is important. I can go to the clinics and see the therapists and doctors for my son...yes my son can get into appointments faster and more frequently which I think has helped his health a lot...just having a car I think makes it easier to get my son enough medicine and health care to keep him OK...and you know my husband works a lot and earns good money which is good because we can dress up our son with cute clothes and good hats so it’s not a problem when we leave the house... “
Maria was thankful that her son’s microcephaly was minor and not as extreme as the cases she had seen online, in the media, or on other children at the clinics. Maria commented that many times a stranger may be unaware of her son’s microcephaly at first. This made Maria hopeful that her son would be able to live a “normal” life. Although hopeful about the future, Maria worried that her son’s health will disintegrate or that his medical services would stop.

“I wake up every day and hope he is still alive. That is not a good way to live. He is at the age where doctors did not think he would ever be. I remember everyone thought he would only live a year…now he is three years old. What will happen in his future? Will SUS stop providing services to him because he is four years old? Will there be new treatments for him? Will there be special schools for him? What do I do? My life is for him now…and I do not know what the future is…. I do not think anybody knows what to do with these babies now…”

Maria shook her head as she reminisced about her dreams of having four or five children. She now felt she could only handle her one son. Her husband said he wanted more children and Maria became angry telling him that it was not an option. This was an issue in her household as the couple often fought over their future. Maria believed she could not emotionally nor financially manage more children and worried people would judge her for having another child:

“People would think I was selfish if I became pregnant again. They know my baby is special and needs a lot of attention. I would not be a good mother if I took more responsibilities now…this life isn’t easy, and people know. And I do not want to be a ‘Zika Mom’ forever…that is how people see me now…so what happens if the next child has a problem? I want to have a normal life separate from that name…Zika will come
back with the rain and I will be unlucky to get it again and have another child with
problems...but my husband thinks I am selfish to not want more children...I don’t
know...”

Maria felt all she had become after the birth of her son was a ‘Zika mom’. Maria characterized
ZIKV as stigmatized because it was often associated with dirty homes, poor women, or
uneducated people. Maria explained the media constantly portrayed favelas, uneducated women,
or filthy homes as locations for ZIKV outbreaks and areas where the ‘Zika moms’ lived. She
described feeling embarrassed knowing people now link her with being unable to keep a clean
home and ignorant of disease prevention. Maria believed the judgement toward her was stronger
than any stigma toward her child. Although a complicated time in their lives, Maria was
cautiously optimistic about the future.

DISCUSSION

ZIKV quickly appeared in 2015, hit epidemic status in 2016, and then six months later
was demoted to endemic status. This swift change from undetected threat, to panicked outbreak,
to complacent endemic has resulted in decreased funding, little media attention, and diminished
programming for those who were impacted by the disease. Women were targeted throughout the
outbreak as they were considered the most vulnerable population due to the chance of vertically
transmitting the disease to their fetus. This attention was removed once the incidence of ZIKV
and CZS began to decline. As this attention diminished, women have been left to attend to both
their needs as well as the needs of their children in an environment that lacks access to
appropriate, adequate, and consistent services.
Pregnancy Beliefs and ZIKV

This study adds to the body of work focused on Brazilian women’s experiences with pregnancy, motherhood, and childcare. A main finding was that women and community members share the belief that negative outcomes during a pregnancy were often indicative of a woman’s failure. Women acknowledged feeling immense pressure to be “perfect” during their pregnancies in hopes of ensuring proper fetal development. Furthermore, women continue to have strong beliefs that immoral behaviors, strong emotional states (i.e. stress and fear), or not getting sufficient sleep, could harm a fetus as has been documented in previous ethnographic work (Calou et al., 2018; Dalsgaard, 2004; Neuhouser, 1998; Scheper-Hughes, 1992). For example, a miscarriage was suggestive of the woman doing something “wrong” during her pregnancy such as partaking in drugs, being unfaithful, not being religious, not eating well, or being lazy. This concept of imprinting is common in traditional ideologies of pregnancy. Many cultures, including many facets of Brazilian culture, believe that dangers to the fetus can arise from lapses in moral or physical behavior of the mother (Dalsgaard, 2004; Neuhouser, 1998; Scheper-Hughes, 1992; Woodhouse, 1982). This study continues to show that motherhood, often intertwined with womanhood, is frequently associated with a moral model of a good woman, a caring person, a submissive wife, a faithful worshipper of God, a compliant patient, and a responsible citizen.

It is important to acknowledge women’s strong beliefs in traditional concepts of pregnancy as it may impact their care-seeking behaviors, perceptions of their pregnancy, fertility decision-making, and ways of protecting the pregnancy. For example, it was common that women believed speaking about ZIKV would jinx their pregnancy or bring on the illness. Women said it was therefore rude to speak about ZIKV with pregnant woman, which is
important as we think about how information about ZIKV should be delivered. It was also considered dangerous to be stressed during one’s pregnancy. This was associated with women being unwilling to seek prenatal care as they felt being diagnosed with ZIKV, or their child being diagnosed with CZS, would cause them to worry for the duration of their pregnancy, therefore causing harm to the child. Since there was no cure for ZIKV, seeking out a ZIKV diagnosis or treatment was futile. Stress stemming from a ZIKV diagnosis was also seen as a strong reason for women to not seek out prenatal care.

*The Role of ZIKV Now*

It has been found that ZIKV still plays a role in these women’s lives as they try to move forward. The women who experienced a stillbirth or miscarriage due to ZIKV cannot be dismissed as we reflect on the outcomes of the epidemic. These women are still experiencing lingering feelings of fear, depressions, and strained social interactions. For many of these women, their experiences continue to impact their fertility decision-making as they think about starting or growing a family. Several interviewees recognized having identity issues since their expected role of “mother” was taken away by ZIKV. Psychological studies within Northeastern Brazil found that, compared to mothers of children without disabilities, mothers of children with CZS are more likely to experience negative mental health outcomes such as stress, anxiety and depression as well as spend substantially more time at home, experience more childrearing difficulties, and suffer from more severe economic hardships (Kotzky et al., 2019; Kuper, 2019, Williams et al., 2019). This ZIKV-induced experience appears to have derailed women’s sense of
self and feelings of being a “good” person or woman creating a higher need for more psychosocial support, childcare services, and health education.

Mothers of children with CZS need more support. Many mothers have had to quit their jobs to become full-time caregivers for their children with CZS. The sacrifice of income, careers, and livelihood to best care for one’s children is an unfair burden disproportionately impacting these mothers. These mothers of the CZS generation have been forgotten by many, yet these women have bound together to create the support, resources, and community they are missing. Together these women learn how to care for their children, how to deal with discrimination, how to advocate for their children’s needs, how to protect each other, and how to juggle the difficult healthcare system. These mothers need their government to extend its aid in a sustainable way that acknowledges current barriers to care and encompasses the needs of both mother and child. Other qualitative studies from this region have documented similar findings which emphasizes the fact that the needs of children with CZS are not being met due to disjointed communication among healthcare providers, within an underfunded system, that ultimately yields inadequate resources and care for the mothers and children (Albuquerque et al., 2018; Carvalho, 2018; Oliveira, et al, 2018; Sá et al., 2017).

Many women who are pregnant now are being left out of the ZIKV conversation. ZIKV not having a role in these women’s lives is dangerous as they may not be aware of ZIKV’s continued ability to affect their pregnancies. Women’s feeling of not being at risk is fueled by healthcare centers and the media stopping their provision of ZIKV awareness, and education, and declining resources specifically for ZIKA and in general. Although the risk of ZIKV is significantly lower, the virus is still endemic in many areas. Women who are currently pregnant still need to be connected to ZIKV health resources.
CONCLUSION

Throughout the epidemic, ZIKV has often been conceptualized as a women’s health issue as the direst outcomes impacted pregnant women. This approach is harmful as it limits the scope of the issue and disproportionately assigns the burden of ZIKV. By placing the sole burden of ZIKV prevention on women it allows outsiders to more easily judge women for negative health outcomes. Women spoke of ZIKV as a one-sided burden with men and fathers being at the outskirts of the mother-centric epidemic. Furthermore, women are in fear of judgement, stigma, and/or community backlash that they or their child may experience having been labeled as a “Zika mom” or a “micro baby”.

The unknown forecast of ZIKV leaves many worried as to what their futures may hold. Participants voiced concerns as to the imminent return of ZIKV, the longevity of resources for children, the use of possible vaccines, and the way this virus could impact future births. Funding and programming for children born with Congenital Zika Syndrome were initially made available for children 0-3 years of age (Ministério da Saúde, 2016; Pereira, 2017). Children are now superseding expectations of longevity in a system that has been documented as unable to meet the demand for the specialized, involved, multifaceted care for the children at any stage of a CZS diagnosis. As the first generation of these children reaches this threshold, questions of continued access to services are on the minds of their mothers. Will the children be able to attend schools? Will medications, physical therapy, and medical resources still be available for those born with CZS as they age?

Resources allocated to women and mothers need to be amplified if they are to be targeted for ZIKV prevention and CZS caregiving. Women earn fewer wages than men, have more
informal jobs, and often cannot work or complete their education as they are responsible for tending to the children. Many women spoke of their male counterpart as being the breadwinner of the family yet often leaving due to unanticipated pregnancies or pregnancy outcomes such as Zika’s. An overlooked outcome of the ZIKV epidemic has not only been the aging generation of children with CZS, but the cohort of women left to care for these children. These mothers need to be recognized and supported as they navigate increased challenges and decreased resources.
CHAPTER 7: DISCUSSION

This dissertation sought to understand the role of ZIKV in the lives of women and children in Fortaleza. Emphasis was placed on how women perceived the ZIKV prevention recommendations, especially those related to pregnancy and fertility decision-making made during the epidemic. This dissertation is unique as it combines these aspects with ethnographic evidence of how the effects of ZIKV persist in the lives of women and children most severely impacted by ZIKV.

The study was broken down into three components, each subsequent component exploring a deeper level of understanding the role ZIKV. Manuscript 1 of this dissertation looked at women’s perceptions toward the prevention recommendations made by the Brazilian authorities during the epidemic. Manuscript 2 of this dissertation targeted one of those recommendations as it focused on women’s fertility decision-making and adhered the recommendation of avoiding pregnancy during the epidemic. The final component, Manuscript 3 of this dissertation, utilized an ethnographic approach to delve deeper into those women’s experiences to understand how ZIKV continues to play a role in the lives of those women and children still being impacted by the disease. These three components were designed to work together to best answer the research questions.

Manuscript 1: ZIKV Recommendations and Response

What do women know about the ZIKV health messages and recommendations? What are women’s perceptions about the feasibility of ZIKV recommendations? What do they actually do to prevent ZIKV infection?
The recommendations made by the Brazilian Ministry of Health during the ZIKV epidemic were found to be missing key components of an effective health education and promotion campaign. Recommendations targeted the middle class and grouped them as one homogenous entity with equal ability to adhere to prevention behaviors. It was found that women’s perceived ability to adhere to ZIKV recommendations was based on their perceived socioeconomic status. This perceived socioeconomic status further impacted their perception of access to resources, risk of disease, and ability to control their health. Women who self-identified as being of a higher socioeconomic class felt somewhat able to adhere to the prevention recommendations as they had better quality resources, access to resources, and cleaner communities. Participants who self-identified as being of a lower socioeconomic class felt unable to adhere to prevention recommendations due to poorer quality resources, lack of access to resources, and less hygienic environments. It is important to have tailored messages and responses that acknowledge the context in which the participant is expected to perform preventative behaviors in order to increase agency and decrease barriers.

**Manuscript 2: Fertility Decision-Making during ZIKV**

_Did, and are women currently, modifying their fertility decisions due to the ZIKV epidemic in Brazil? Why or why not?_

Women were not modifying their fertility decisions due to the ZIKV epidemic. The notion of avoiding pregnancy was generally seen as unrealistic, unavoidable, and undesired. The recommendation to avoid pregnancy due to ZIKV was seen as unrealistic since pregnancy was believed to be something very difficult to control. Lack of control was attributed to religious ideologies, social pressure, and/or a distrust of contraceptive resources. As with Paper 1,
socioeconomic status played a major role in how women viewed their ability to adhere to the recommendation – here it is the recommendation to avoid pregnancy.

The inevitability of motherhood was strongly voiced in this study, as motherhood was felt to be an essential role for women in their community. Women interviewed felt a need to fill this role and do so to the best of their ability. Even those who wished to postpone pregnancy for the purpose of economic benefit (finishing school, building a career, earning enough money to save) explained the reason of these aspirations was to be better prepared to provide for their children in the future. The recommendation to avoid pregnancy due to ZIKV was perceived as not only unrealistic but counter-cultural. This recommendation defied the social consensus that women should fulfill a destiny of motherhood and that all families needed children to have a meaningful life.

Manuscript 3: Adverse pregnancies and children born with CZS in Fortaleza

What were the experiences of women who had adverse pregnancies associated with ZIKV and their experiences raising children with Congenital Zika Syndrome?

This study found that women and children who experienced severe ZIKV-related health outcomes such as adverse pregnancies and birth defects, continue to feel the impact of the disease. Women who had miscarriages or stillbirths caused by ZIKV are still experiencing negative health outcomes and strained social interactions. The mothers of children with CZS are falling through the cracks as Brazil gets farther from the peak of the epidemic. Accessing adequate resources for these children is time-consuming, expensive, and difficult to navigate. Many mothers spoke of their male counterpart as being the breadwinner of the family but having left due to unanticipated pregnancies or pregnancy outcomes. Mothers are concerned for the
future as many of these children are presenting with more health issues as time treks on. The financial, emotional, and daily sacrifices of mothers and families taking care of these children with CZS are not being acknowledged and more aid needs to be given to ease the lives of caregivers and children.

7.1. SUMMARY

Overall the ZIKV recommendations and response by Brazilian authorities during the epidemic appear to have been established without evidence-based approaches to health promotion and health education. ZIKV prevention recommendations did not use this approach because they assumed a homogenous level of knowledge, agency, and desire among the Brazilian population. The recommendations were additionally one-sided, targeting women and unfairly placing the burden of prevention on them. Excluding men from recommendations and response created barriers for women to adhere to recommendations such as the sexual transmission of ZIKV and postponing a pregnancy. The recommendations were also found to be flawed as they did not consider the context in which the recommendations were disseminated - therefore excluding key factors such as socioeconomic status, gender roles, social norms, and access to resources. These issues were consistent in all three branches of the study as these ideas are echoed in each paper.

Paper 1 of this study found that ZIKV was perceived as no longer being a threat, therefore no longer an issue. Papers 2 and 3 took a deeper approach and found ZIKV was only believed to have a role in one’s life if the woman had experienced an adverse pregnancy due to the disease. Paper 2 found that although adverse pregnancies were feared, women generally felt in little control of their fertility decision-making. Paper 3 investigated experiences associated
with these adverse pregnancies. Adverse pregnancies such as miscarriages and stillbirths heavily impacted participants’ mental health and continue to affect their social relationships. Mothers of children with CZS felt ZIKV was a permanent part of their lives. These mothers felt abandoned by the government as the aid allocated to these children continues to diminish as we get farther from the peak of the epidemic. As in Paper 1 and Paper 2, Paper 3 found that women of higher socioeconomic status were better equipped to care for a child with CZS although they still struggled to appropriately care for their child. Furthermore, as we’ve seen in Paper 1 and Paper 2, Paper 3 identifies that the response for these mothers and children lacked acknowledgment of the context in which these individuals live. The response has not adequately addressed barriers to accessing resources, the gendered nature of single-motherhood care, nor the socioeconomic stress of raising these children.
CHAPTER 8: CONCLUSION

The recommendations from this dissertation have been broken down into two categories. The first list of recommendations gives guidance as to how to modify ZIKV messaging for future cycles of the disease. The second list of recommendations speaks to improvements that can be made to epidemic responses in general.

8.1 ZIKV SPECIFIC RECOMMENDATIONS

8.1.1. Recommendations need to be ZIKV-specific.

The recycled dengue material led individuals to ignore the ZIKV messaging as viewers may think they are already aware of the pertinent information. Redundant approaches additionally create complacency within the communities. Future messaging should not solely associate ZIKV with dengue as it ignores the sexual transmission of the disease and the possibility of adverse pregnancy and birth outcomes.

8.1.2. Recommendations related to vector control need to provide detailed instructions for household mosquito mitigation and community-level support to aid the mitigation of mosquitos.

Cleanliness of the home is often associated with vector control as opposed to concrete vector control strategies. Future messaging should work with these already present ideas of cleanliness, but additionally, include more evidence-based approaches to vector control. Participants reported feeling discouraged from preventative behaviors because of accumulations of trash or stagnant water in their communities. It is therefore suggested that messaging be paired with a community-level strategy to assess the need for
education, adherence, trash removal, and water upkeep. Pairing vector-control recommendations and community-based activities could increase adherence.

8.1.3. Recommendations need to acknowledge both men’s and women’s role in ZIKV.

Messaging needs to reflect both party’s equal ability to become infected and transmit the disease. By solely targeting women for ZIKV prevention, it places an unfair burden on them. If half the population is not working toward a common goal of prevention, ZIKV mitigation cannot be reached. Men are needed to be engaged in both mosquito prevention as well as sexual transmission prevention of ZIKV. A one-sided approach to mitigating this disease is not a reasonable solution. Additionally, by only acknowledging women as the sole caregivers for children with CZS it normalizes the idea that single women should be raising these children. Fathers need to be included in the discussion of ZIKV and CZS to encourage partnership in prevention and childrearing.

8.1.4. Recommendations need to better discuss the sexual transmission of ZIKV.

This form of transmission needs to be advertised more frequently and openly. It is acknowledged that the scientific evidence supporting this form of transmission came late in the epidemic therefore, dissemination of this information was delayed. It is also acknowledged that this form of transmission is not as common as mosquito transmission. It is imperative to equally promote utilizing a condom as a form of ZIKV prevention. To not acknowledge men’s ability to become infected with the disease and possibly transmit the disease through sexual intercourse, places women (especially pregnant women) in a highly vulnerable position to not only become infected but to then carry the burden of
blame for why they or their fetus was infected with the disease.

8.1.5. Recommendations focusing on pregnancy avoidance need to acknowledge feasibility.

To recommend women not become pregnant due to ZIKV assumes women have both the ability and desire to do so. Furthermore, it assumes all women have equal means to postpone a pregnancy in a country where pregnancy termination is dangerously illegal. This recommendation needs to focus on the availability, agency, and social norms related to pregnancy avoidance in their communities. If this type of messaging is used, it must be paired with elements that bolster the environment in which this “decision” is made. This would ideally aid in ensuring women have the supplies and support to postpone a pregnancy if they desire to.

8.1.6. Response to mothers and children impacted by CZS

An outcome of the ZIKV epidemic has not only been the generation of children with CZS but the cohort of women left to care for these children. Mothers are struggling to access the copious amount of services their children need. The primary concern for these mothers is what the future will hold for their children. Women earn fewer wages than men, have more informal jobs, and often cannot work due to the necessity to tend to the many needs of their children. Mothers’ inability to work due to the need to care for children should not be overlooked by the government or health authorities at this time. These mothers need to be recognized and supported as they juggle increased financial stress and decreased resources.
8.2. GENERAL EPIDEMIC RECOMMENDATIONS

8.2.1. **Recommendations need to be developed utilizing best practices in health promotion.**

This entails utilizing theories of behavior change and acknowledging the context in which the recommendations are made. Blanket recommendations that speak to the population as a homogeneous entity are not effective because they assume all individuals have the same education, resources, and ability to adhere to the recommendations. It is recommended that future approaches be more conscious of the needs of the populations especially as factors such as socioeconomic status, gender roles, and social norms may impact one’s ability to protect themselves from infection.

8.2.2. **Recommendations need to be tailored and updated for each response.**

Utilizing recycled information creates a desensitized population that may not be retaining all the needed information. Repeated approaches to outbreaks or epidemics can also create complacency among the population. This is particularly dangerous if the population does not perceive the responses as effective or if the population feels a low level of risk.

8.2.3. **Recommendations should be removed from the media with caution.**

Once an epidemic begins to subside it is better to continue promoting messages at a lower volume, than to remove them completely. Removing all messaging creates the illusion that the threat is completely gone. Although there may be a lowered risk, a threat still exists, and messaging should reflect that.
8.2.4. **Responses to epidemics need to be sustainable.**

Epidemics are cyclical in nature; therefore, infrastructure should be established to mitigate the impact of its inevitable return. There is also a need for sustainable solutions for those most severely impacted by the epidemic. Sustainable responses need to be made to accommodate those populations who have long-term health issues associated with the disease whether it be physical, mental, or emotional.

8.2.5. **Responses need to include a social science component from the start.**

Social science cannot be an afterthought in epidemic responses. Social science approaches allow responses to collect needed nuanced data to aid in the development, implementation, and evaluation of responses, programming, and messaging. By utilizing social science approaches at the start of the response, other aspects of the response such as the quantitative, biomedical, and epidemiological components can be strengthened.

8.3. **LIMITATIONS**

No study is without limitations. The following are the main limitations of this study

- Qualitative methods open a study to interviewee bias (e.g. social desirability bias) as well as interviewer bias. Being well-trained in qualitative methods, being familiar with the region, and having piloted the instruments extensively diminish the risk of these biases

- This study sample is small and therefore findings are not generalizable to the entire Brazilian population. Saturation was reached with this study and findings compared to other studies in the region.
• The timing of this study is a limitation as it asked participants to recall information from several years prior to the interview. Data collection took place at the end of 2018, three years after the onset of ZIKV in Brazil. This study taking place in 2018 did allow for better documentation of the experiences of mothers raising children with CZS.

• The testing mechanism for ZIKV is not completely accurate therefore participants may have a skewed perception of their disease exposure/ the extent of ZIKV exposure in their community.
REFERENCES


doi:10.1371/journal.pone.0190024


Christofferson R.C (2016). Zika virus emergence and expansion: Lessons learned from dengue and Chikungunya may not provide all the answers. *The American Journal of Tropical Medicine and Hygiene.* (23) 14.


*Medical Anthropology Quarterly*. https://doi.org/10.1525/maq.2004.18.2.183


doi:10.1016/j.rhm.2016.11.008


with the public during an outbreak. Retrieved from:

https://apps.who.int/iris/bitstream/handle/10665/69138/WHO_CDS_2005.32.pdf?sequence=1&isAllowed=y


https://apps.who.int/iris/bitstream/handle/10665/204348/zikasitrep_5Feb2016_eng.pdf;jsessionid=C4D7C85278B0B1A470C392959FD77E94?sequence=1


https://www.who.int/immunization/research/vaccine_pipeline_tracker_spreadsheet/en/


APPENDIX

Figure 1: WHO’s Timeline of ZIKV Recommendations and Discoveries.

March 29, 2015
- Brazil notifies WHO of an illness characterized by skin rash in northeastern states. Zika was not suspected at this stage, and no tests for Zika were carried out.

May 7, 2015
- Brazil's National Reference Laboratory confirms Zika virus is circulating in the country.
- WHO/PAHO release an epidemiological alert for possible Zika virus infection in Brazil

July 17, 2015
- Brazil reports neurological disorders associated with a history of infection, primarily from the north-eastern state of Bahia

October 30, 2015
- Brazil reports an unusual increase in the number of cases of microcephaly among newborns.

November 11, 2015
- Brazil declares a national public health emergency as cases of suspected microcephaly continue to increase.

November 17, 2015
- WHO/PAHO issue an epidemiological alert asking countries to report increases of congenital microcephaly and other central nervous system malformations. Brazil reports the detection of Zika virus in amniotic fluid samples from 2 pregnant women, whose fetuses were confirmed by ultrasound examinations to have microcephaly.

November 28, 2015
- Brazil detects Zika virus genome in the blood and tissue samples of a baby with microcephaly and other congenital anomalies; the baby died within 5 minutes of birth.

December 1, 2015
- WHO/PAHO issue an alert on the association of Zika virus infection with neurological syndrome and congenital malformations in the Americas.

January 5, 2016
- Researchers report the first diagnoses of intrauterine transmission of the Zika virus in 2 pregnant women in Brazil whose fetuses were diagnosed with microcephaly, including severe brain abnormalities, by ultrasound. Although tests of blood samples from both women are negative, Zika virus is detected in amniotic fluid.

January 7, 2016
- Ophthalmologists in Brazil report severe ocular malformations in 3 infants born with microcephaly.

January 22, 2016
- Brazil reports that 1,708 cases of Guillain–Barré syndrome have been registered by hospitals between January and November 2015.
- Most states reporting cases are experiencing simultaneous outbreaks of Zika, chikungunya, and dengue.

February 1, 2016
- WHO declares that the recent association of Zika infection with clusters of microcephaly and other neurological disorders constitutes a Public Health Emergency of International Concern.

February 2, 2016
- WHO published the guidance on prevention of sexual transmission of Zika virus in February 2016. The guidance was updated on 30 May 2016.
February 4, 2016
- Brazilian health officials confirm a case of Zika virus infection transmitted by transfused blood from an infected donor.

March 8, 2016
- The Zika Emergency Committee announces that evidence is increasing of a causal relationship of neurological disorders with Zika virus.

May 28, 2016
- WHO issues public health advice regarding the Olympic Games which includes advice on preventing transmission of Zika virus.

June 3, 2016
- Emerging evidence suggests a broader range of possible complications for babies born to women affected by Zika virus.

July 2016
- WHO publishes a Target Product Profile for Zika vaccines which defines the desired characteristics for optimal vaccines, such as safety, period of protection, shelf life and number of doses required to protect against Zika.

July 22, 2016
- Fiocruz Institute Pernambuco announces that it detected Zika virus in *Culex quinquefasciatus* mosquitoes collected in houses in the city of Recife, Brazil.

August 29, 2016
- WHO is mapping social science research for the Zika response. Knowledge, Attitudes and Practice (KAP) surveys and other social science research allows responders to better address people's needs at community level, thereby contributing to the overall public health response to Zika virus and associated complications.

September 1, 2016
- WHO Director-General Dr Margaret Chan convened the 4th meeting of the IHR Emergency Committee on Zika virus and associated complications. Based on the Committee's advice, the Public Health Emergency of International Concern was continued.

September 6, 2016
- WHO has published its interim guidance on the prevention of sexual transmission of Zika virus using all available evidence. The recommendation for both men and women is to practice safer sex or abstinence for a period of six months, whether they show Zika symptoms or not.

September 7, 2016
- Based on a systematic review of the science literature up to 30 May 2016, WHO concluded that Zika virus infection during pregnancy is a cause of congenital brain abnormalities, including microcephaly, and that Zika virus infection is a trigger of Guillain-Barré syndrome.

October 14, 2016
- WHO updates the fact sheet on microcephaly to include congenital Zika virus syndrome, a range of manifestations of varying severity reported among newborns that were exposed to Zika virus in utero. The manifestations include malformations of the head, seizures, swallowing problems, hearing and sight abnormalities. Other outcomes associated with Zika virus infection in utero may involve miscarriages and stillbirths.

November 18, 2016
- The WHO Director-General declares the end of the Public Health Emergency of International Concern regarding microcephaly, other neurological disorders and Zika virus.

February 1, 2017
- WHO updates information on vaccine research and development. More than 40 Zika vaccine candidates are in the pipeline and 5 are entering Phase I trials.
Figure 2: Conceptual Model of Fertility Decision-Making as a Response to The ZIKV Epidemic
Figure 3: Socioeconomic Class in Brazil

### Brazilian Criteria Thresholds

<table>
<thead>
<tr>
<th>SEL</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>45 - 100</td>
</tr>
<tr>
<td>B1</td>
<td>38 - 44</td>
</tr>
<tr>
<td>B2</td>
<td>29 - 37</td>
</tr>
<tr>
<td>C1</td>
<td>23 - 28</td>
</tr>
<tr>
<td>C2</td>
<td>17 - 22</td>
</tr>
<tr>
<td>D-E</td>
<td>0 - 16</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SEL</th>
<th>Brazil</th>
<th>Southeast</th>
<th>South</th>
<th>Northeast</th>
<th>Midwest</th>
<th>North</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>2.9%</td>
<td>3.6%</td>
<td>3.4%</td>
<td>1.4%</td>
<td>4.2%</td>
<td>1.8%</td>
</tr>
<tr>
<td>B1</td>
<td>5.0%</td>
<td>6.2%</td>
<td>6.2%</td>
<td>2.7%</td>
<td>5.3%</td>
<td>3.4%</td>
</tr>
<tr>
<td>B2</td>
<td>17.3%</td>
<td>21.0%</td>
<td>20.6%</td>
<td>10.5%</td>
<td>18.7%</td>
<td>11.7%</td>
</tr>
<tr>
<td>C1</td>
<td>22.2%</td>
<td>25.3%</td>
<td>28.0%</td>
<td>15.1%</td>
<td>23.0%</td>
<td>17.9%</td>
</tr>
<tr>
<td>C2</td>
<td>25.6%</td>
<td>25.4%</td>
<td>24.8%</td>
<td>25.6%</td>
<td>27.5%</td>
<td>26.3%</td>
</tr>
<tr>
<td>D-E</td>
<td>27.0%</td>
<td>18.5%</td>
<td>17.0%</td>
<td>44.7%</td>
<td>21.3%</td>
<td>38.9%</td>
</tr>
</tbody>
</table>

**TOTAL: 100% 100% 100% 100% 100% 100%**

<table>
<thead>
<tr>
<th>SEL</th>
<th>9 MRs</th>
<th>POA</th>
<th>CWB</th>
<th>SP</th>
<th>RJ</th>
<th>BH</th>
<th>BSB</th>
<th>SSA</th>
<th>REC</th>
<th>FOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>4.3%</td>
<td>3.7%</td>
<td>5.4%</td>
<td>4.8%</td>
<td>3.5%</td>
<td>3.5%</td>
<td>9.9%</td>
<td>4.1%</td>
<td>2.0%</td>
<td>3.4%</td>
</tr>
<tr>
<td>B1</td>
<td>6.6%</td>
<td>6.5%</td>
<td>8.2%</td>
<td>7.5%</td>
<td>5.9%</td>
<td>5.7%</td>
<td>9.6%</td>
<td>5.2%</td>
<td>4.4%</td>
<td>4.3%</td>
</tr>
<tr>
<td>B2</td>
<td>19.5%</td>
<td>20.7%</td>
<td>24.3%</td>
<td>23.1%</td>
<td>17.5%</td>
<td>18.4%</td>
<td>22.0%</td>
<td>13.8%</td>
<td>13.2%</td>
<td>12.8%</td>
</tr>
<tr>
<td>C1</td>
<td>24.3%</td>
<td>27.0%</td>
<td>27.6%</td>
<td>28.4%</td>
<td>23.2%</td>
<td>24.0%</td>
<td>22.0%</td>
<td>18.1%</td>
<td>16.7%</td>
<td>15.0%</td>
</tr>
<tr>
<td>C2</td>
<td>25.9%</td>
<td>27.0%</td>
<td>22.8%</td>
<td>25.0%</td>
<td>26.6%</td>
<td>27.5%</td>
<td>21.7%</td>
<td>28.5%</td>
<td>28.5%</td>
<td>26.1%</td>
</tr>
<tr>
<td>D-E</td>
<td>19.4%</td>
<td>15.1%</td>
<td>11.7%</td>
<td>11.2%</td>
<td>23.3%</td>
<td>20.9%</td>
<td>14.8%</td>
<td>30.3%</td>
<td>35.2%</td>
<td>38.4%</td>
</tr>
</tbody>
</table>

**TOTAL: 100% 100% 100% 100% 100% 100% 100% 100% 100% 100%**
**Figure 4: Fieldworker Training**

<table>
<thead>
<tr>
<th>Day</th>
<th>Content</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Overview of the project and an overview of the training program</td>
<td>Icebreaker, introduction, lecture</td>
</tr>
<tr>
<td>2</td>
<td>Overview of Rapid Assessments what is a rapid assessment, how will it be utilized in this project, what activities are associated with this RA</td>
<td>Activity 1: How to record observations Activity 2: True or False Zika facts</td>
</tr>
<tr>
<td></td>
<td>ZIKV basic information (transmission, prevention, risk)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>ZIKV health messaging in the community: how to spot it, how to evaluate it, how to record those observations</td>
<td>Lecture</td>
</tr>
<tr>
<td>4</td>
<td>ZIKV prevention in the community: how to spot it, how to evaluate it, how to record those observations</td>
<td>Lecture</td>
</tr>
<tr>
<td>5</td>
<td>Exam on ZIKV information and Rapid Assessment methodology</td>
<td>Exam and clarification of incorrect answers</td>
</tr>
<tr>
<td>6</td>
<td>Interviewing 101 What is it, how does this apply to Rapid Assessments, how does this apply to the project</td>
<td>Activity 3: Interview your neighbor</td>
</tr>
<tr>
<td>7</td>
<td>Informal interviews, structured interviews, and in-depth interviews.</td>
<td>Lecture</td>
</tr>
<tr>
<td>8</td>
<td>What makes a good interviewer? Technique, biases, and limitations</td>
<td>Lecture</td>
</tr>
<tr>
<td>9</td>
<td>What to look for in the field and common errors in interviewing</td>
<td>Activity 4: Interviewing</td>
</tr>
<tr>
<td>10</td>
<td>Exam on interviewing techniques and methodologies. Explanation of the study and discussion of team assignments</td>
<td>Exam and Team Assignments</td>
</tr>
</tbody>
</table>
Figure 5: RAA Guide

Zika in Fortaleza: Response of a cohort of women aged 15-39

Qualitative Guide for Rapid Assessments

This guide can be printed as a question sheet to take with you to the interviews as a reminder. Use a notebook to follow the interview. When you transpose your field notes, right after the interview, and enter your notes on your computer, organize them using this guide as a template. Make your answers as complete and "rich" as possible and appropriate.

Name of Interviewee _____________________________________
Interviewer ________________________________________________
Interview Number _________________________________________
Date ______________________________________________________
Time ______________________________________________________
Duration __________________________________________________

SECTION 1. INTERVIEWEE INFORMATION

1.1 Full Name:

1.2. Age

1.3 Schooling:

1.4. Skin Color:

1.5. Religion:

1.6. Occupation:

1.7. Are you from Fortaleza?
   (If the interviewee was not born in Fortaleza, inquire as to the amount of time they have lived in Fortaleza, where they were born, if they live in an urban or rural area, and if they are still tied to the place they were born.).

1.8. Can you become pregnant?
   (If not, why can you not get pregnant? Did you tie your tubes, get your uterus removed, issues with infertility?)

SECTION 2. KNOWLEDGE ABOUT ZIKA VIRUS, MOSQUITOS, AND MICROCEPHALY
2.1. Knowledge about Zika virus

2.1.1 What do you know about Zika virus?

*If not stated in the answer:*

- Who can be affected by zika?
- What are the symptoms of zika?
- How do you know if it is zika?
- How is the disease transmitted?
- What is the treatment of the disease?
- What is the difference between zika, dengue, and chikungunya?
- How can it affect a pregnancy and babies?
- Did you do something different in this pregnancy? What?
  - In this pregnancy, have you taken any protective measures against zika that you did not have before?
  - If so, which ones? *(do not ask: clothes, repellent screens, windows and doors - section recommendations)?*
- Do you know if there is a difference getting zika at the beginning or the end of the pregnancy?
- Can Zika affect your newborn baby? How does it get affect?

The purpose of these questions is to find what the respondent knows and what she truly believes to be true - there will probably be differences. You will always discover new things with each answer. These questions are just the starting point.

2.1.2 You have seen, read, or heard what information about zika?

- Where?
- What did you hear?
- How did you or are you responding to this information?
- Do you feel you are at risk for getting this disease?

2.1.3 What do you know about the health ministry's recommendations about Zika?

For each recommendation mentioned, ask:

- What does each recommendation mean?
- How important is the recommendation?
- Why are the authorities saying this?

2.1.4 The following recommendations will be used to supplement the information level of the previous question. After she commented on what she knows, explore other recommendations not mentioned by the interviewee, such as: wearing sleeves, repellent use, screens on windows, use of mosquito nets

Recommendations:

- To use repellent
- Keep doors and windows closed or screened
- Wear long sleeved clothing and pants
- Use bednets
- Use condoms in sexual relationships
- Eliminate mosquito breeding sites inside and outside the home
• Cover and wash water containers, such as water tanks and other containers.
• Avoid or delay pregnancy during the zika epidemic period
  • Where did you hear this from?
  • What do you think about this particular recommendation?

Note: In consolidating the interviews, do not mix the recommendations mentioned by the interviewee and the ones you added later.

2.2. Knowledge about the mosquito vector

• Do you know the name of the mosquito that transmits Zika?
• Where does the mosquito come from (where does it reproduce)?
• How do the mosquitos transmit zika?
• Can they transmit zika to you with only one bite (if the answer is more than one, as how often do you believe it needs to be bit).
• Authorities say the mosquito that carries Zika stings all the time, not just at night, what do you think of this?
• Sometimes the bites of this mosquito are so mild that we can not feel them. Do you think this is true?
• What can you do to avoid being bit? Can you really avoid it?
• For you, is there a season (months and / or season) of the year with the greatest threat from Zika? If yes, when?
• What can be done to control mosquitoes and reduce the risk of Zika?

2.3. What do you know about microcephaly?

If no response, inquire further:
• What is it?
• What are the symptoms?
• Who can be affected?
• What are the causes?
• *add* is it serious?

SECTION 3: PREGNANCY, REPRODUCTIVE INTENTIONS, AND ZIKA

Interviewee reproductive history:

• Number of pregnancies: __________________________ (previous and current)
• Any Miscarriages? ______________________________ (If yes, inquire when and how)
• Number of births: _______________________________

3.1. Pregnancy

• Are you pregnant?
  o (If not pregnant, explore whether they intend to become pregnant and if the zika epidemic in recent years influenced the decision to postpone pregnancy)
• Did you tell your partner as soon as you found out?
  o How long did you wait to tell him?
  o How did he react?
- How do you feel about being pregnant during the zika epidemic?
- If you've been to the primary health unit, did the doctor or nurse tell you something about Zika?
  - What?

3.2. Reproductive Intentions and Zika virus

- During the past 12 months, did you or your partner want to have a baby?
  - Note if the woman's and partner's wishes were different
  - Why or why not?
- If you did not want a baby, what did you do to avoid pregnancy?
  - Do you think you were able to act as you wanted? Why or why not?
  - How difficult was that for you to do? Why?
- Have you ever thought in the last year that you might be pregnant? What did you do?
  - (If the respondent reports that she went to a primary health unit to take the pregnancy test, ask if she received any advice, what, and if this advice or guidance resonated and made sense to her)?
  - *If not already mentioned* Some authorities are advising women to not get pregnant for a year or more. What do you think of this?
  - *Ask this question if it did not come up earlier in the interview*. Because the Zika virus can be transmitted through sex, health authorities recommend the use of condoms, either alone or in combination with other methods. What do you think?

3.3. Influence of the zika virus on the reproductive intentions of their friends?

- Do you have any friends whose decision to become pregnant was influenced by zika?
- Do you know someone who did not get pregnant because of zika? What did she do?
- Do you know anyone who had zika during pregnancy? What happened?
- Do you talk a lot about pregnancy and zika in your conversations with your friends?
  - What do they say about it?
  - If they do not talk about zika, why?
  - What do they say about pregnancy)?
- Do you talk about the ideal time to get pregnant?
  - What is the best time?
  - What is the ideal number of children?
  - What do you plan to do with Zika's threat regarding time and number of children?
- Do you have friends want to have children now? Why?
- For your friends, when is the ideal time (of her life) to get pregnant?
  - Why is this the ideal time? How has Zika affected this?
- When one of your friends becomes pregnant, does she always want the baby?
  - If not, why? What can she do about it? How has Zika affected this?

Remind your respondents: These questions apply to the male partner of their female friends:

- Do your friends' partners already talk about babies or about being parents?
- When do they say they want to have children?
- Has Zika changed or affected the intentions of these men to be a father?
- How do you think they would behave if their partner became pregnant?
- What can a woman do if her partner wants her to get pregnant and she does not?
3.4 In general who decides: (ask why and how it works)

- When to become pregnant? Man, woman, both, neither
- Whether or not to use something to avoid getting pregnant? Man, woman, both, neither
- Whether or not to use a condom? Man, woman, both, neither
- Whether or not they have sex? Man, woman, both, neither
- What can a woman do if her husband / boyfriend wants to have sex and she does not?

SESSION 4: FAMILY PLANNING

4.1. Do you and your partner talk a lot about contraception?
   - If yes: what do they say? If not, for what reasons do they not talk about it?
4.2. What words do you and your boyfriend use to talk about contraception or family planning
   - like natural method, condom, diaphragm, pill ...?
4.3. For each of the above family planning methods, ask:
   - If it is common, how regular is this use?
   - What are the benefits and discomforts of using it?
4.4. Free list: What are good reasons to use contraceptive methods?
4.5. Free list: What are good reasons to stop using contraceptive methods?

SECTION 5: SCENARIOS

Let's read the following scenario (scenes). After each part, please tell us what you think about the woman and her decision.

5.1 Maria is 28 years old, lives in the Bom Jardim neighborhood in a small house near her mother, has been married to Tiago for five years and has never had a baby. Although Mary is using family planning, she has just gotten pregnant. What should she do?

5.2 Maria and James talk about Zika's risks to the child. James is really worried about Zika and the baby. He wants Mary to have an abortion. What should she do?

5.3 Maria decides to keep the baby but asks James to help clean the yard and repair the house to reduce mosquitoes, promising to wear long sleeves and long pants and using repellent, and using condoms while she is pregnant. James mocks Maria's decisions, but offers help to clean the house. He does not want to use condoms. What do you think about this?

5.4 Maria has a fever, goes to the basic health unit and discovers that she has Zika. What should she do? (If she is not covered in the previous scenario.) Maria is not sure whether she wants the baby or not. She thinks she does not want to and plans to end the pregnancy. What do you think about this?

5.5 Does Mary decide to keep the baby? What do you think?

5.6 Maria goes to the basic health unit and does an ultrasound. The ultrasound shows that the baby is affected by Zika. What should she do?
SECTION 6: UTILIZATION OF HEALTH SERVICES – BASIC HEALTH UNIT

6.1 Do you frequently go to health facilities?

6.2 Which basic health unit do you use regularly?

6.3 When did you start seeking care at this basic health unit?

6.4 How do you usually get to the BHU?

6.5 How long does it take?

6.6 How many times a month do you go to this BHU?

6.7 Why did you choose this BHU?

6.8 Did someone there at the BHU talk to you about Zika and pregnancy?
   What did they say?
   How did they speak to you about this topic?
   Judgmentally, briefly, kindly, confused, etc.

6.9 If you had Zika or had a fever, would you go to the basic health unit?
   • Why?
   • When would you go?
   • How would you get there?

→ What about if it was a fever and a rash?
   • Why
   • When would you go?
   • How would you get there?

6.10 Before you go to the basic health unit, who would you talk to about Zika? *confusing*
   • If you thought you had it? Did you think you had Zika and talked to someone about it?
   • This person thought you were with Zika and said something about?

6.11 Do you ask about Zika, pregnancy, birth control or sexual intercourse? *at the BHU?
   • If so, do you feel comfortable? (Ask why the answer is yes or no)?

6.12 How satisfied are you with the kind of care the doctors or nurses give you?
   • Very satisfied / satisfied / not so satisfied / dissatisfied. Why?

6.13 Have you had any problems in the past when you attended this basic health unit?
   • What problems?