by Eni Nako

A THESIS

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Honors Baccalaureate of Science in Biochemistry and Biophysics (Honors Scholar)

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AN ABSTRACT OF THE THESIS OF

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Abstract approved:_		
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The purpose of this study was to examine pregnant Puerto Rican women's perspectives on the Zika virus threat. Using data collected from open-ended, semistructured interviews and observational field notes, we aimed to understand the degree to which Zika contributes to maternal stress. How concerned are pregnant women in Puerto Rico about Zika and its potential impact on their babies? Do they feel they have enough information to avoid vertical transmission? How concerning is Zika relative to the other daily stressors pregnant Puerto Rican women must navigate? Interview transcripts from twenty-five participants were consensus coded by three researchers; four key theme emerged: 1) Pervasive socioeconomic stress; 2) Zika as a government conspiracy and politicized issue; 3) Fear of microcephaly and Zikarelated birth defects; and 4) Gendered stress, inequality and social pressures. Our findings indicate that while Puerto Rican and international public health professionals are heavily focused on Zika education and transmission prevention, women in our study experienced far less Zika-related stress than non-Zika related stress. Pregnant Puerto Rican women are primarily concerned with economic, social, and familial/relationship-level stressors. Zika is often seen as a more easily controlled stressor relative to the larger micro- and macro-level stressors that emerge from Puerto Rico's current economic crisis. Any Zika-related stress is experienced primarily in the first trimester and as a compounder of already existing economic distress. Findings have implications for the structure and delivery of maternity care in Puerto Rico, as well as for Zika prevention messaging.

Key Words: Zika, Puerto Rico, Microcephaly, Pregnancy, Stress

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Introduction

The Zika virus is an arthropod-borne virus transmitted by the Aedes species of mosquito. The Zika virus was first discovered in the Zika forest of Uganda in 1947 and isolated from a monkey. Though Zika traveled along parts of Africa and Asia, there were no serious Zika outbreaks until 2007, when cases of an illness with dengue-like symptoms emerged in Yap, Federated States of Micronesia. Though symptoms included rash, conjunctivitis, and arthralgia, the illness was clinically distinct from dengue, and further testing identified Zika virus RNA in patient serum. Outbreaks in Southeast Asia and the Western Pacific followed. The Puerto Rico Department of Health reported the first case of Zika on December 31, 2015 in the southeastern region of the island (See Table 1).

The US Centers for Disease Control and Prevention (CDC) has placed Puerto Rico on Level 2 alert, urging travelers heading to Puerto Rico to cover exposed skin and use repellents containing DEET.⁵ According to the CDC, the virus has infected mosquitos on the island, and this insect is now spreading it to Puerto Rico's inhabitants at an alarming rate. Zika can also be transmitted sexually or to the fetus through pregnancy; the latter is known to cause serious birth defects especially when the virus is contracted during the first trimester of pregnancy when fetal development is most vulnerable to teratogens.⁵ As of May 24, 2017, there have been 35,431 laboratory confirmed cases of Zika in Puerto Rico, accounting for nearly 97% of Zika cases in the United States territories.⁶ In fact, the Puerto Rican Zika database contains the highest number of laboratory confirmed cases in the world, with nearly all 78 municipalities reporting infections.^{7,8} The CDC, in partnership with the Puerto Rico

Department of Health (PRDH), created a Zika registry and surveillance system to follow outcomes of pregnancies with possible Zika virus infections up through early childhood until the age three years.⁹

Our study examined the perspectives of Puerto Rican women on Zika and the stress they experienced during their pregnancies as a result. Data were gathered through the use of open-ended, semi-structured interviews and observational field notes. We sampled for diversity and spoke to a voluntary group of pregnant or recently pregnant women (n=25) from different economic and educational backgrounds to better understand the widespread effects of Zika on the Puerto Rican population. By encouraging women to share their narratives of Zika- and non-Zikarelated stress during pregnancy, we aimed to gain a deeper, ethnographic understanding of the ways Puerto Rican women navigate the stressors of pregnancy, including, but not limited to, Zika. How concerned are pregnant women in Puerto Rico about Zika and its potential impact on their babies? Do they feel like they have enough information to avoid vertical transmission? How concerning is Zika relative to the other daily stressors pregnant Puerto Rican women must navigate? Ultimately, answers to these questions will be used to inform public heath messaging in Puerto Rico.

El Zika Quick Facts:

- ZIKV is a mosquito-borne virus associated with debilitating neurological conditions (including microcephaly) in infants whose mothers contract the disease during pregnancy
- ZIKV is transmitted via mosquitos, and sexual contact
- First case of Zika-related microcephaly in Puerto Rico identified in October of 2016
- As of May 24, 2017, there have been 35,431 clinically confirmed cases in Puerto Rico
- Approximately ten percent of those affected in Puerto Rico are pregnant women
- 11% of women infected with ZIKV in the first trimester will have affected infants

Background

In the summer of 2014, Oregon State University researchers Cheyney and Horan¹⁴ conducted a preliminary study with maternal and infant health care providers in San Juan, Puerto Rico. This study was designed to explore the institutional and political-economic factors associated with poor maternal and infant health outcomes, such as preterm birth, through the process of "studying-up". ¹⁵ Cheyney, Horan, and two pre-medicine undergraduate research assistants collected 20 in-depth, semi-structured interviews with maternal and infant health care experts identified as keystakeholders, asking them to describe what they see as the primary concerns for and barriers to improving maternal and infant health outcomes in Puerto Rico; Puerto Rican maternal and infant health outcomes are the worst in almost every category for all US states and territories.

Participants in this pilot study included midwives (*parteras*), obstetricians, pediatricians, perinatal psychologists, lactation consultants, nutritionists, obstetric nurses, and public health professionals, all of whom work in San Juan and the surrounding metropolitan area. Interviews were transcribed, consensus-coded, and analyzed for concept saturation. Cheyney and Horan identified several key themes or issues that experts viewed as negatively influencing Puerto Rico's maternal and infant health outcomes with the greatest consensus around the role of poverty and maternal stress on poor outcomes, especially prematurity. Political and economic inequities within the existing health care delivery system were also consistently described as contributing to poorer-than-expected health outcomes for mothers and babies.

Furthermore, stress from poverty and inequality was described as acerbating all of the other concerns (like lack of access to quality prenatal care and poor nutrition) identified in these key-stakeholder interviews. Importantly, concerns for maternal stress levels emerged even before Zika had been identified and declared a public health crisis in Puerto Rico, leading to a need to assess the degree to which Zika may be adding to already high levels of maternal stress thought by many to be driving the island's poor birth outcomes. This project, overseen Cheyney and Horan, was designed to help fill this gap in the research on Puerto Rico's maternal and infant health crisis.

Methods

After obtaining institutional review board approval from Oregon State

University, pregnant and recently postpartum women in Puerto Rico were invited to

participate in open-ended interviews on their experiences of Zika- and non-Zikarelated stress during pregnancy through flyers distributed at prenatal care sites in San
Juan, Puerto Rico and surrounding areas (Appendix 1). Flyers invited women to share
their stories of maternal stress, detailed that the length of the interview would be 3060 minutes and explained that interviewed would be conducted in either English or
Spanish. All participants were gifted climate-appropriate, baby carrying wraps for
their participation. Women who were interested in participating self-identified by
contacting the researchers either by phone or email.

After potential participants were given the opportunity to have all questions regarding the study answered, they were verbally consented into the study, screened for inclusion criteria and interviewed in a place that was convenient for them (i.e.; home, physician's office). Eni Nako and Holly Horan conducted all interviews, asking women to describe their experiences of being pregnant and the role stress (both general and Zika related) played in months leading up to their births. Interviews began with broad questions as we asked volunteers about how they viewed and coped with stress during pregnancy. As the interviews progressed, the questions became more directed as we prompted participants to elaborate on certain aspects of their lives such as work- and family-related stress, and finally, to the Zika virus (Appendix 2).

Audio recordings of the interviews were de-identified, transcribed verbatim, and if the interview was conducted in Spanish, translated into English and reviewed again by all three researchers (Cheyney, Horan, and Nako) The interviews were then analyzed and consensus coded to identify any recurring themes.¹⁶ This was done

through multiple codings wherein the authors separately analyzed the interviews, and then met to discuss similarities and differences in emergent codes or themes. Any differences were discussed with reference to the transcribed texts until we came to consensus regarding recurring four key themes (discussed below). This approach allowed the researchers to identify the core key themes or concepts that participants used to describe their experiences of being pregnant and navigating multiple stressors during the early days of Puerto Rico's Zika epidemic. Throughout the preliminary process of coding and discussion of themes, we continued to interview, stopping recruitment once we reached concept saturation wherein no new themes were emerging from the data.

Results

We interviewed twenty-five participants from San Juan, PR and the surrounding areas between July and September of 2016, all of whom self-identified as Latina/Hispanic. Twenty-three of these mothers provided insight on stress and Zika. As shown in Table 2, our sample includes a mix of first time and experienced mothers, ranging from 22 to 47 years of age with varying levels of education. Through analysis of interview texts we were able to identify four distinctive, recurring themes or sources of stress: 1) Pervasive socioeconomic stress; 2) Zika as a government conspiracy and politicized issue; 3) Fear of microcephaly and Zikarelated birth defects; and 4) Gendered stress, inequality and social pressures. These are discussed in detail below:

Table 2. Demographic Characteristics (n=25)

Characteristics				
Race, n				
White	8			
Mixed (Mestizo)	5			
Other	11			
Not Documented	1			
Color, n				
White	13			
Brown	10			
Not Documented	2			
Age, mean (range)	32.2 (22-45)			
Marital Status, <i>n</i>				
Partnered	7			
Married	16			
Divorced	2			
Pregnant at time of interview, <i>n</i>				
Yes	14			
No	11			
Parity, <i>n</i>				
Primiparous	15			
Multiparous	10			
Highest Level of Education, n				
Some University (No degree)	2			
Associate's Degree	4			
Bachelor's Degree	5			
Master's Degree	10			
Doctorate Degree	3			
Not Documented	1			

Theme One: "We all stress about money": Pervasive Socioeconomic Stress

Financial stress and economic struggle were, by far, the most common themes discussed by participants who believed these stressors to be a shared by mothers in other parts of the middle- and low-resource world, as well as by mothers living in poverty in high-resource nations. Some participants framed economic stress in terms of lifestyle: "Well, I think we all share, around the industrialized world, we all share the same reasons for stress...especially capitalist societies, where we want to have [a] certain lifestyle or quality of life." Another participant echoed this concern as she

expressed her worries related to the Puerto Rican "economic crisis." This crisis refers to the almost \$73 billion debt that Puerto Rico is responsible for. 19 In an effort to reframe their economic situation, Puerto Rico enacted the Puerto Rico Corporation Debt Enforcement and Recovery Act into law in 2014, which would have allowed Puerto Rico to create a restructuring plan for their debt. However, the US Supreme Court invalidated the law in Commonwealth of Puerto Rico v. Franklin California Tax-Free Trust in 2016, claiming bankruptcy code preempted the Act. 20 Soon after, in June of 2016, the United States passed into law PROMESA, the Puerto Rico Oversight Management and Economic Stability Act, 21 which allows for nearly total U.S. control over Puerto Rico's economy, effectively further hindering their right to self-governance. Participants often specifically highlighted the impact of financial stress on women: "It makes people stressed all the time, thinking of how they are going to resolve their necessities. To eat, how to pay for all those services, and nothing relates to the issue like unemployment. The lack of opportunities for, in particular for the women. I think that women experience more stress."

According to the Bureau of Labor Statistics, the Puerto Rican unemployment rate in March of 2017 was 11.5%, and it is also currently following a downward trend.²² The US Census Reports between 2011 and 2015 showed that 45% of the Puerto Rican population works a "civilian" jobs, yet only 40.2% of those individuals are women.²³ This means that only 18.09% of the Puerto Rican civil workforce is made up of women.

Participants' discussions of economic instability were also intertwined with worries over social change and political concerns. One participant described how

these go hand in hand: "Stress can come due to many social factors too, such as the economy and the politics of our island." Another participant discussed the instability she experiences: "We are just experiencing so many unknown changes, political changes, along with the societal changes, with the education changes, with the values changes, with everything." With the passing of PROMESA, 21 additional power was given to the US government under the guise of economic relief, leaving less power in the hands of the Puerto Rican people. Uncertainties around policy implementation and perceived limitations on self-governance have entrenched the divide between the US and some of our Puerto Ricans participants. Navigating these changes can mean a lot of uncertainly and insecurity for women, particularly because of the unknown effects that any policy changes might have on their health or the overall wellbeing or their families. One participant spoke about this uncertainty saving: "Sometimes the stress is related to the burden of not know what's going to happen next here." Another participant shared her experience: "We're tired, we're restless and worried about the future, about our jobs. We have basic needs and demands that are not being met."

Economic concerns were echoed by multiple participants: "I understand that the environment, that the economy, it matters for our health." Stress related to "not knowing what will come next" economically, politically and socially was described as being "on the minds" of most pregnant women as they are considering the future and the conditions of the world they are bringing a baby into. One mother, when asked how she describes stress, said, "Other words or concepts that describe stress? I would say.... the word 'uncertainty'. Uncertainty, I would relate it a lot to stress. Uh, what other word? Worry. Basically uncertainty and worry."

Theme Two: "Every day I think that it was invented": Zika as a government conspiracy and politicized issue

The theme of Zika as government conspiracy emerged largely as a consequence of an explicit lack of faith in both the local Puerto Rican government as well as a profound skepticism over the United States intentions and the latter's historical and contemporary colonial relationship with Puerto Rico. Participants described feelings of uncertainty and distrust that led them to question whether the Zika threat was "even real." Much of this government distrust can be linked to the sterilization of Puerto Rican women in the 1940s and 1950s²⁴ that participants see echoed in the language of current counter-Zika family planning recommendations which assert that individuals possibly exposed to Zika should wait before trying to conceive. 25 As a post sterilization society, many Puerto Ricans, and women in particular, are skeptical of any health campaigns supported by the US government, especially when they aim to curb reproduction in any way: "So, we have had other mosquito-borne illness for a long time, like dengue and chikungunya, and now all of a sudden we should delay childbearing and tourists should not come here. Right...this is suspicious to us."

One participant used the idea of a fabricated threat to reduce stress on herself and her family. When discussing comforting her daughter who worried for her pregnant mother and unborn sibling, she said: "She goes, 'mama take care of yourself, of the Zika.' And I just assured her, 'Baby, that was made up by humans, for a political reason, so don't worry about Zika'."

Much of the skepticism around the Zika threat was related to the mediums in which information is dispersed by the media. Some participants argued that they needed access to "unbiased information" but that this is nearly impossible to find: "I think it's different because of the way that we bring the information here. I don't agree with that. It's the opposite from my own view. Because it's not the same to give you information without any emotional aspect of my own opinion, to give you information just to educate yourself, or allow you to make your own point of view. Here, we don't do that. We just give you information in a way that makes you change your point of view to mine. So that part, the manipulation, that is what brings me stress." Another participant echoed this argument in regards to the media: "The status of the country, everything makes you worry. Really, it's the media. What they make of it [the Zika threat], that is the problem. It's a bad day for something interesting."

Theme Three: "I worried about mosquitos all the time": Fear of microcephaly and Zika-related birth defects

Though not all of the Zika-related educational initiatives were welcomed, the message of the threat of birth defects had reached these participants loud and clear, and most were worried, or had worried some time in their pregnancies. The additional stress that they felt in their lives because of the Zika threat affected their daily routines and schedules. Participants described the stress of having to closely monitor the size of the baby's head: "It was very scary and frustrating that a mosquito would bite me. Every time that I would go do a sonogram, I wanted to make sure that the baby was well, that the baby was developing well, that the baby wouldn't have

problems...every time that [we had] a sonogram, my husband would be even more stressed than me. We needed to know that the head was the average measurement and that everything was going alright." Another participants spoke about her desire to give birth to a healthy baby: "That is a theme that has given me a lot of stress this pregnancy. Zika. In fact, I want to give birth already, to avoid exposing myself to the disease... Well, I kind of want to give birth now. At least, I want the days to go by fast, so the baby doesn't come out affected."

Interestingly, Zika-related stress and fear of problems with fetal development co-existed with skepticism over whether the risks were being overstated as a means of population control, and many participants were simultaneously stressed about Zika and unsure whether the threat was "real." Regardless, most were considerably affected by worry over Zika, though a majority expressly described Zika worries as less than other worries over basic needs related to food, shelter, health care, employment, and personal safety. While Zika-related stress certainly emerged as a common theme, it is also noteworthy that some participants never mentioned it as a stressor until asked specifically about it. Even though the Zika threat clearly affected maternal stress levels and added additional stressors to participants' lives, it was not the primary concern for most mothers. Although the threat existed, other, more controllable issues were at the forefront of many participants' minds.

In addition, women described not only being under stress to produce a healthy child, but also asserted that this was far more difficult to do so in the midst of Puerto Rico's simultaneous economic and health crises: "There is a lot going here. It is a very stressful time to be pregnant. You have Zika and you have the terrible economy.

And they are related of course. You see Miami does not have a Zika epidemic." Previous research on maternal health, environmental stress and fetal outcomes has demonstrated a link between high perceived maternal stress and poor infant mental development. As such, findings from this study, and for this theme in particular, are of concern: Zika-fear itself may contribute to or exacerbate already poor maternal and infant health outcomes in Puerto Rico.

Theme Four: "In Puerto Rico, we give a lot of importance to what other people think": Gendered stress, inequality, and social pressures

In addition to the stressors mentioned above, participants also described some stressors they argued were particular to Puerto Rican culture and to women especially. One participant who had lived in the United States for some time compared her US and Puerto Rican experiences: "I moved back to Maryland, and there you don't have to deal with family, you don't have to deal with Puerto Ricans having opinions over everything you do in your life. So if you decide to breastfeed your kid until he's five, and you decide to have a home birth, you don't have that pressure of family giving their opinions like they do in Puerto Rico where everyone is in your business and putting pressure on you." Narratives revealed the prevalence of what has been called "familism" in the Puerto Rican context; familism is a social structure where the needs of the family are more important and often take precedence over the needs of any of the individual family members.²⁷

In this context, family can be both a source of stress and a mitigator of it.

Another participant spoke of her relationship with her family and how that affected

her stress: "Family here, culturally, families are very, very close here, and they all get in your business. They mean well, and they all love you, but there are no boundaries. So you are bombarded with their problems and they want to be [in] your life and make decisions that you should be making. Their worry for Zika becomes your worry for Zika. They all mean well but it's, it's a mess. I love them, but this is my life and this is your life, and there are just no boundaries." The participants who spoke about Puerto Rican family values and the stressors that can result from them had often spent time in the United States. Through comparing their experiences on the island to those in mainland US, they were able to discern familial relationships as sometimes problematic, at least as far as they could function to increase stress. Participants often described their stress as coming from "people around you." As one said: "In Puerto Rico, we give a lot of importance to what other people think." The importance of the opinions of others, including when it comes to medical and reproductive decisionmaking, and the respect for family involvement may stem from the honor culture that is widely present in Latin American communities.²⁸

Discussion

Interview and textual data collected and analyzed for this study enabled us to identify four key themes that help to convey the types, sources, and severity of specific stressors Puerto Rican women may experience during pregnancy. These include 1) Pervasive socioeconomic stress; 2) Zika as a government conspiracy and politicized issue; 3) Fear of microcephaly and Zika-related birth defects; and 4) Gendered stress, inequality, and social pressures. Analysis of these themes reveals

their interdependence and highlights the ways history and institutional distrust impacts participants' perceptions and responses to public health messaging about the Zika virus.

Our findings indicate that while Puerto Rican and international public health professionals are heavily focused on Zika education and transmission prevention, women in our study experienced less Zika-related stress than non-Zika related stress. Pregnant Puerto Rican women are primarily concerned with economic, social, and familial/relationship-level stressors. Zika is often seen as a more easily controlled stressor relative to the larger micro- and macro-level stressors that emerge from Puerto Rico's current economic crisis. Any Zika-related stress is experienced primarily in the first trimester and it compounds already existing economic distress.

Findings also have implications for the structure and delivery of maternity care in Puerto Rico, as well as for Zika prevention messaging. The perspectives of participants bring to light some of the issues surrounding public health messaging and the distribution of information.

By taking into account Zika- and non-Zika-related stressors, this investigation brings to light the consequences of public health campaigns that do not take into account the local, historical, and political-economic aspects of target areas. In understanding the severity of the themes highlighted in this research, future campaigns focused on maternal health can better tailor their approach to mothers in the target population, and in so doing, may avoid adverse effects caused by public health messaging.

It is important to note here that two of the stressors commonly reported by interviewees were directly tied to the Zika outbreak. Puerto Rico is no stranger to mosquito-borne diseases as it is home to Dengue and Chikungunya viruses, ²⁹ neither of which were cited as stressors. Zika-linked paranoia as perceived by some participants can largely be tied to the sensationalization of the crisis and constant public health campaigns in the region. The danger here is in the continuation of these public health "scares" and the effects they could have on maternal health. Previous work has shown that distress in the mother during pregnancy can cause lower intellectual development in the children, as well as neurodevelopmental disorders like schizophrenia, depression, and autism. ^{26, 30, 31} Additionally, traumatic childbirth can inhibit the connection between mother and infant. ³² If mothers are scared that their babies will be born with Zika-related birth defects, they will worry about their pregnancy and their birth, causing further distress post-partum.

Conclusion

The purpose of this study was to examine pregnant Puerto Rican women's perspectives on the Zika virus threat. Specifically, we aimed to understand the degree to which Zika contributes to maternal stress. Our findings suggest that Puerto Rican pregnant women experience more non-Zika- than Zika-related stress due largely to socioeconomic and familial issues. In addition, the Zika threat is described as a concern even though some participants also, simultaneously, described some skepticism regarding the reliability of information provided on the virus by local and national governments. These findings highlight the deep, institutional distrust that

exists between the US and this territory for many Puerto Rican people. Our findings also suggest that public health campaigns can increase their effectiveness by taking into account the local histories and cultural beliefs of their target populations.

Empowering people with culturally informed public health messaging may help to reduce both the adverse effects of the Zika virus *and* the stress that emerges from the scare tactics used in Zika campaigns themselves.

Epilogue

In reflecting back on my ten week experience in Puerto Rico collecting the data analyzed for this thesis, and also thinking about what stood out to me as I read and coded the interviews, I see that my own history and personal narrative played a role in how I came to understand Zika and pregnancy on the island. My bicultural background as an Albanian immigrant to the United States allowed me to see some of the cultural themes present in the narratives of participants and observations made while in the field. In particular, I was sensitive to issues of national identity and the often-uneasy relationship between Puerto Rico and the United States. In addition, the continuation of a strong, Puerto Rican culture and identity following US colonization parallels the strong traditional ties I feel to my own culture even though I have grown up in the United States. My positionality and life experience also enabled me to see the role of familism and honor culture, as these are also central to Albanian culture. I am grateful to the study participants and to our research collaborators in Puerto Rico not only for the opportunity to participate in cross-cultural research they enabled, but

also for helping to remind me that certain aspects of culture remain regardless of exposure to other dominant (and sometimes dominating) ways of life.

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How does stress affect your pregnancy?



Share your experience in a 30 – 60 minute interview!

Holly Horan, a researcher, birth and post-partum doula, and mother from Oregon State University wants to hear your story!

For more information contact Holly Horan:

E-mail: horanh@onid.orst.edu **Cell-Phone:** (319) 429 – 3758

Study Title: Territorial Biologies and the Premature Body: Maternal Stress and Gestational Age at Delivery in Cayey, Puerto Rico Principal Investigator: Dr. Melissa Cheyney, Oregon State University

Interviews can be in English or Spanish

What does the word "stress" mean to you?

What are some ways that stress has affected you in your life?

Is there another term or concept that you would use to describe these experiences, besides the word "stress"?

If so, where did you learn about these various concepts of stress?

How do you think stress in Puerto Rico is different from other places in the world such as the United States or Latin America?

How do you think stress is similar in other places of the world?

Why is stress in Puerto Rico similar or different to these other areas?

How do you reduce or eliminate stress?

How do you include these practices in your daily life?

Who or what helps you reduce or eliminate stress?

What causes your stress to become worse?

How do you believe stress affects your health?

What are some negative wats stress affects your health?

What are some positive ways stress affects your health?

What kind of care do you receive when stress affects your health?

How does stress affect your pregnancy?

What causes this stress?

How has your experience of stress changed since becoming pregnant with this baby?

How has your experience of stress changed since becoming pregnant for the first time?

How do you think stress affects your health and the health of the baby?

Who or what else is affected by stress during pregnancy?

What do you do to reduce stress during pregnancy?

How does stress in pregnancy affect birth outcomes?

What other information is important to discuss, in regards to stress and pregnancy?

How was your pregnancy affected by the Zika crisis?