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Perceptions of Health Care, Information, and Social Support Among Women Affected by Zika Virus Infection During Pregnancy in Two U.S. States

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Abstract

Objectives—To understand the information needs and experiences with health care and social support among women with confirmed or possible Zika virus infection during pregnancy.

Methods—We conducted in-depth interviews with 18 women whose pregnancies were part of surveillance efforts in two states, Pennsylvania and Virginia. Using a semi-structured guide available in English and Spanish, we asked women about their experiences. We conducted a thematic analysis using NVivo 11.

Results—Only one participant reported that her infant had been diagnosed with health problems related to congenital Zika virus infection. Most participants said they received the information they needed about Zika virus and their infant's medical care. Most participants primarily spoke Spanish and described satisfactory experiences communicating with providers, either using a mix of Spanish and English or using an interpreter. Coordination of care and clear communication among different providers was a key factor in participants' satisfaction with health care received. Participants noted high levels of stress around the uncertainty associated with Zika virus exposure during pregnancy.

Conclusions for Practice—Although participants reported satisfaction with care, they also reported high levels of anxiety and challenges coping with the uncertainties along their journeys. Study findings support the need for guidance for providers about how to talk with women about

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Declarations

Conflict of interest These authors declare that they have no conflict of interest.

Zika virus infection during pregnancy and specifically how to discuss the uncertainties about diagnosis and outcomes.

Keywords

Zika; Pregnancy; Health care; Information needs

Introduction

The Zika virus outbreak in the Americas was a public health emergency that impacted pregnant women and caused severe health consequences for infants (Delaney et al., 2018; Honein et al., 2017; Rice et al., 2018). Between December 2015 and March 2018, more than 7400 pregnancies in the United States and its territories had a laboratory result of confirmed or possible Zika virus infection (Centers for Disease Control and Prevention [CDC], 2018). Most cases were travel associated or acquired in areas with local transmission (Hall et al., 2018). Infants infected with Zika virus during pregnancy can have serious health problems, including brain abnormalities, eye abnormalities, and neurodevelopmental problems. These outcomes occur in about 5–10% of infants born with confirmed Zika virus infection (Reynolds et al., 2017; Shapiro-Mendoza et al., 2017).

Few studies have been conducted that outline what pregnant women who were exposed to Zika virus understand about the virus, the risks to their infants, and the evaluation and care their infants will need. To address this gap, we conducted in-depth interviews with women who had confirmed or possible Zika virus infection during pregnancy to assess what information women received, the care their infant was receiving, challenges they faced in caring for their infant, and barriers to receiving health care and support services.

Methods

We conducted interviews with women whose pregnancies were part of United States Zika Pregnancy and Infant Registry (USZPIR) surveillance efforts in two states, Pennsylvania and Virginia. These states were identified through interviews with the state health department staff to determine the feasibility of implementing this study with women from state registries. RTI International's Institutional Review Board and the Office of Management and Budget approved all data collection.

Sample

All women enrolled as of July 2018 in the USZPIR in Virginia and Pennsylvania (not including Philadelphia) and who had liveborn infants were eligible for the study. A total of 101 women were eligible to participate in the study: 47 from Pennsylvania (not including Philadelphia) and 54 from Virginia.

Recruitment

The health departments sent introductory letters in both Spanish and English to eligible women to inform them about the study and provided instructions for contacting the study team about voluntary participation. Each letter included $2 to cover any telephone costs

associated with participating in the interview. The health departments also placed follow-up calls to eligible women approximately 1 week after sending the letters. We then contacted women who agreed to participate in the study to schedule a 1-h telephone interview.

Data Collection

Because little is known about the experiences of women in the USZPIR, we used grounded theory as a basis for developing a semi-structured interview guide, which allowed us to seek out patterns from interview responses. The major domains of the guide included questions to elicit women's initial concerns about Zika virus infection, information and resources received, the transition from prenatal care to pediatric care, and social support received.

We developed a Spanish-language interview guide, which was reviewed by two bilingual experts and was field tested. Prior to conducting the telephone interview, the interviewer obtained verbal consent from the participant and permission to audio record the conversation. A trained, female bilingual interviewer conducted each interview in the participant's preferred language. Interviews were audio recorded, and a second bilingual team member joined each interview to serve as a note taker. Following each interview, we sent the participant a $40 gift card and written resources about Zika virus in her preferred language.

Data Analysis

Transcripts were produced from interview notes and audio recordings. We conducted a thematic analysis of qualitative data using NVivo 11 (QSR Software), with a predetermined coding structure that mapped to the interview guide. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guided the reporting of our methods findings (Tong et al., 2007).

Results

From August to October 2018, we conducted 12 interviews with women in Virginia and six interviews with women in Pennsylvania for a total of 18 interviews with women who possibly had Zika virus infection during pregnancy. Fourteen of the 18 interviews were conducted in Spanish at the request of the participants.

Participant Characteristics

Participants were primarily Hispanic/Latina, either employed for wages or homemakers, were married, and had one or two children. One third of participants had a household income of less than $10,000, and one-third had a household income between $10,000 and $30,000. Most participants reported having Medicaid (n = 12) (Table 1).

Infant Outcomes

Only one participant reported that her infant had been diagnosed with health problems related to congenital Zika virus infection. The remaining 17 participants reported that their infants were not diagnosed with any health problems associated with congenital Zika virus infection.

Information Provided

Most participants said they received the information they needed about Zika virus and their infant's health care and reported receiving this information when they first learned they had been/might have been infected with the virus. Some participants said this information came from a health care provider and that they were informed their infant could potentially have severe developmental issues or possibly even die. Some participants shared that a doctor said that not much could be done medically, and they would have to wait until the pregnancy progressed or the infant was born to know whether their baby was affected by Zika virus infection. Other participants said they received printed materials about Zika virus and that they were offered materials in Spanish. These materials described general information about Zika virus infection, such as symptoms and modes of transmission, and information about pregnancy and caring for an infant affected by Zika.

A few participants said they either did not receive any information or that they did not remember receiving any specific information. Notably, two participants said they did not read the materials they were given because they were afraid of knowing more about the potential impact on the infant.

Although participants were primarily Spanish speakers, most described satisfactory experiences communicating with health care providers, either using a mix of Spanish and English or an interpreter. However, two participants noted serious communication challenges; one participant expressed that it would have been helpful if an interpreter had been available throughout the process.

Women's Concerns

Participants' primary concerns were about the impacts on their infant—whether the infant would be infected, develop normally, or have lasting health effects—and how they would care for a child with physical or cognitive disabilities. Women tended to have more questions and concerns when their infant's outcomes were uncertain, and fewer questions and concerns when their infant's growth and development were on track. Two participants said they would have liked more information on how the virus could impact their child's long-term health.

Stress of Uncertainty

Several participants described the stress of waiting throughout their pregnancy and not knowing what the impact on their infant would be. Clear communication from their prenatal provider about the actual risk of their infant being affected by Zika virus infection was helpful for women. Participants said that receiving reassurance from their providers that their infant may not be affected by Zika virus infection was helpful to them during this period of uncertainty.

Coordination of Care

Coordination of care and clear communication among different providers was a key factor in perceived satisfaction with health care services received. All but one of the participants reported that one pediatrician or specialist regularly cared for the infant since birth and

generally one provider was “in charge” of the infant’s care. Participants described seeing a variety of specialists, but most felt that their providers worked well together. Many participants suggested that good communication and coordination among these providers was integral to the successful outcomes for their infants. Participants also described how doctors kept them informed about their infant’s health or how they appreciated having the opportunity to talk with multiple doctors at each step of the process. A few participants felt that their providers did not work well together because of a failure to communicate or coordinate with each other.

Participants reported high levels of satisfaction with the care they received. Participants said providers were very attentive and concerned about their infant’s health. Participants also noted that they felt their infant received high-quality care; they had a good dynamic with the provider; the provider offered clear explanations, and the provider was familiar with their case.

Participants indicated that frequent check-ups, particularly visits that included ultrasounds, were the most helpful aspect of prenatal care that helped them cope with the uncertainty of Zika virus’s impact on their infant.

Discussion

We explored how women with confirmed or possible Zika virus infection during pregnancy learned about the care their infants needed and their experiences with care. The women we interviewed were primarily Spanish speakers, lower income, and Medicaid recipients. Only one participant reported that her infant had health problems because of exposure to Zika virus; as a result, most of the findings from this study pertain to the experiences of women who reported their infants appeared healthy at the time of the interviews, which were primarily conducted when the children were between ages 1 and 2 years.

Participants described receiving a variety of materials and information about Zika virus, with health care providers and supplemental online information as the primary sources for this information. Notably, some participants said they did not read the materials they received because of fear of knowing the potential outcomes for their infants. This reaction underscores the anxiety many women felt coping with the numerous uncertainties about their exposure to Zika virus and potential adverse infant outcomes.

Participants described high levels of satisfaction with the care they received, including coordination of their infant’s health care. Most participants were primarily Spanish speakers however, most said they were able to communicate well with their providers. However, the findings did reveal language barriers as a challenge for some participants.

Continued uncertainty remains about the long-term effects of congenital Zika virus infection, although increasingly there is evidence of additional health effects, such as epilepsy, vision problems, and developmental delays (Satterfield-Nash et al., 2017). For providers, communicating in the context of these scientific uncertainties is challenging.

However, literature suggests that if the provider is reassuring and empathetic and appears confident and comfortable with uncertainty, keeping patient care as the main concern, patients can better accept uncertainty, and their anxiety is reduced (McGovern & Harmon, 2017). Our findings support that observation. Women were reassured because providers were familiar with the infant's case, attentive, and showed concern for the infant's health. These characteristics describe a therapeutic patient–caregiver/provider relationship, which is a central component of patient-centered care.

Interpretation of these findings is subject to several limitations, including the small sample of women from only two states, a low response rate, and the potential for inaccurate recall of their experiences. The women who participated in the study are not representative of all women in the USZPIR and results are not generalizable. Given that only one woman in the sample had an infant with adverse health outcomes, the data about health care experience may reflect more positive outcomes and experiences.

Conclusions for Practice

Although not generalizable, study findings revealed key themes that can inform public health efforts around communication and education for health care providers, families, and the public. Specifically, we suggest the following be created and disseminated:

- Guidance to providers about how to talk with pregnant women about Zika virus infection during pregnancy and specifically how to discuss the uncertainties about diagnosis and outcomes. Guidance may include talking points, such as language for providing reassurance to reduce anxiety.
- Up-to-date and accurate online information in multiple languages. Information for pregnant women and new mothers could include guidelines for check-ups and tests for their infants in easy-to-use formats, such as checklists or calendars, and tips for talking with health care providers (e.g., suggested questions).
- Information for providers about educational resources, encouraging them to point women to up-to-date and accurate information and resources.
- Guidance to health care providers on the need for and coordination with mental health professionals and other support services to help women and families affected by Zika virus infection cope.

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Significance

Few studies have been conducted that help us understand what pregnant women who were exposed to Zika virus infection understand about Zika virus, the evaluation and care their infants will need, and their perceptions of services received. This qualitative study provides insight into the experiences of 18 women enrolled in the U.S. Zika Pregnancy and Infant Registry, which collects information about pregnancies exposed or potentially exposed to Zika, in Virginia and Pennsylvania, regarding the information, health care, and support they and their infants needed and received.

Table 1

Participant characteristics

	Total (N = 18)
Age (years)	
18–24	6
25–34	8
35–44	4
Race	
White	8
Black or African American	3
American Indian or Alaska Native	1
Other	6
Ethnicity	
Hispanic or Latina	16
Not Hispanic or Latina	2
Employment	
Employed for wages	9
Out of work	1
Homemaker	8
Marital status	
Never married	3
Married	12
Living with partner	2
Separated	1
Number of children in home (includes child in registry)	
1	8
2	7
3	3
Age of child in registry (in months, at time of interview)	
< 12	3
12–23	13
≥24	2
Education	
Less than high school	5
High school	4
Some college, no degree	3
Associate or bachelor’s degree	5
Graduate or professional school/degree	1
Income	
< $10,000	6
$10,000-under $30,000	3
$30,000-under $50,000	1

	Total (N = 18)
$50,000-under $70,000	1
$70,000-or higher	1
Don’t know	6
Health coverage	
Private insurance coverage	4
Medicaid or medical assistance	12
None	1
Don’t know	1
Residence type	
House	8
Apartment	10