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Women's Health Perceptions and Beliefs Related to Zika Virus Exposure during the 2016 Outbreak in Northern Brazil

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Abstract. During the 2016 Zika pandemic in Brazil, women's perceptions of infection risk, ability to adhere to Zika prevention strategies, or access to services following exposure were not emphasized in the public health response. Women in Fortaleza, Brazil, responded to a questionnaire on social factors related to perceived Zika risk and access to health care in June 2016. Data were coded using prespecified categories, and response frequency was reported. Of 37 respondents, most reported a lack of public services to support mosquito control (n = 19) or delayed access to reproductive health care (n = 14). Only 22% described specific maternal risks or fetal outcomes as a consequence of Zika infection. Respondents indicated an overall disconnect between public health efforts and women's perceptions of their reproductive control, including limited support concerning microcephaly in infants. Interventions targeting Zika may require a greater emphasis on strengthening health systems and infrastructure to realistically prevent transmission.

INTRODUCTION

The 2016 Zika outbreak in Brazil received global attention because of widespread incidence, detection of negative fetal outcomes, and the public health response. Control efforts were primarily top-down, intensive vector-control campaigns coupled with dissemination of information to the public as it evolved during the pandemic.[1] During the initial stages of the pandemic when the relationship between Zika and reproductive outcomes was unclear, mixed messages and rumors were commonly circulated on social media.[2] In a study of Zika-related social media posts, 7.5% of posts were found to be misleading; rumors included conspiracy theories about Zika's spread, misinformation about vaccine availability, and confusion about sexual transmission.[3–5] Yet, few on-the-ground studies were conducted with women about their needs, perceptions of risk, and ability to adhere to prevention strategies.[6,7] Gaps in knowledge and practices, particularly among women of childbearing age, exacerbate a critical public health risk for both Zika transmission to women and subsequent vertical transmission to their fetuses, resulting in a long-term health burden for families and communities. Poverty, poor sanitation, lack of healthcare access, and lower education may lead to both increased risk of Zika transmission because of increased *Aedes aegypti* habitat and lowered ability to provide long-term care for an infant with congenital Zika syndrome (CZS).[8,9]

Zika virus, which is primarily transmitted by *Ae. aegypti* mosquitos and secondarily via sexual contact (and potentially through blood transfusions), is mild or asymptomatic in most cases, so its incidence in recent outbreaks is underreported.[10,11] However, for women who are pregnant or become pregnant following Zika infection via an infected mosquito or sexual partner, even asymptomatic Zika infection can be associated with CZS. Despite the link, only a small proportion of Zika-exposed pregnancies result in CZS.[12] This estimation may change as the threshold for what constitutes diagnosable CZS is still evolving as affected children reach developmental milestones.[13,14] Congenital Zika syndrome encompasses a broad range of neurodevelopmental and neurosensory alterations in children exposed in utero, among which the most apparent manifestation is microcephaly.[15,16] Nearly one-third of infants in a Brazilian cohort born after exposure to maternal Zika infection in 2016 have abnormal neurodevelopment, vision, and/or hearing.[17]

The long-term consequences of CZS are worsened in the context of inequitable healthcare access in Latin America.[18,19] For women living in poverty, having a child who requires intensive therapy and medical treatment will only exacerbate the health inequities commonly faced in Latin America because of social, economic, and educational inequity. The short- and long-term health needs of affected families must be anticipated, especially where medical care is insufficient and difficult to access. At the community level, allocation of already-limited resources to the special medical and educational needs of children with CZS may not be feasible without dedicated public health support.[20] Less immediately obvious neurological impacts of Zika, such as poor vision or hearing loss, are also being observed and will continue to impact communities at the population level over time.[21–23]

Risk for sexual transmission of Zika virus was a minor focus in prevention campaigns, particularly regarding women's ability to comply with recommendations to avoid pregnancy or use a barrier method (e.g., male or female condom) during pregnancy. Low-income Brazilian women have reduced or limited access to birth control and abortion than their middle-class peers.[24] The dual risks of mosquito-borne and sexual transmission of Zika, coupled with the higher prevalence of unwanted pregnancies among low-income women, underscore the need to understand the dynamics of risk perception about Zika in urban-dwelling women living in poverty.[25] We undertook a small-scale study during the height of the Zika pandemic in 2016, to preliminarily identify barriers to Zika-related healthcare access and knowledge in a high-risk low-income urban population in Fortaleza, Brazil.

MATERIALS AND METHODS

A short questionnaire was administered in a community served by a local nongovernmental organization (NGO) in Fortaleza, Brazil, in June 2016 to elicit women's perceptions of the Zika pandemic. Academic researchers partnered with a

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community-based NGO to purposively sample female residents served by the NGO. Families live at a very high population density, and houses are built in a pseudo-condominium style (where different floors/apartments are added over time). There is no formal or informal census in this area, and the area is only partially recognized by the government as legitimate construction. Questionnaire content was informed by NGO staff and literature review. Nongovernmental organization staff (F. F. M. and C. d. S. M.) reviewed the tool for face validity, readability, and quality of translation. The study was approved and deemed minimal risk by the Institutional Review Board of the University of Arizona [1605588735].

Purposive sampling with snowball recruitment was conducted with individuals who lived within an approximately four-block radius near the NGO, whereby NGO staff members invited women known to them through their programming, who subsequently referred acquaintances to the study. Participation was limited to women older than 18 years. The approximate size of the larger neighborhood (borough) in Fortaleza area was between 40,000 and 50,000 individuals, although the size of the neighborhood area surrounding the NGO facilities is poorly estimable.

Using a questionnaire with open-ended (n = 10) and closed-ended (n = 32) items, respondents were invited to verbally expand on their provided answers to each question. Five content categories were included: general demographic data, general and specific experiences of the health system, perceptions of women's community health care, perceptions of Zika, and perceptions of social issues. Quantitative questions were measured on a five-point Likert-type scale (strongly disagree to strongly agree), but participants were encouraged to use the interview format to elaborate on their answers with anecdotes or comments. Items were initially developed in English, then translated to Portuguese (E. J. A.), and then discussed in a think-aloud format in Portuguese (E. J. A., F. F. M., and C. d. S. M.) to ensure appropriate translation.

The questionnaire was administered face to face and audio-recorded while the interviewer (E. J. A.) recorded responses to prepared questions and notes on paper forms. To circumvent literacy issues, questions and consent statements were read aloud in Portuguese. Verbal consent was audio-recorded in place of signatures.[26,27] Participants were either interviewed privately at the NGO community center or at their homes after a formal introduction and invitation by NGO staff. To maximize participation, no data were collected on anything that could be perceived by respondents as personal identifiers (e.g., respondent's age or level of education) although number of children (and children's ages) was deemed by partners as an acceptable proxy for women's ages. The median maternal age at first birth in Brazil is 21 years, but it is disproportionately earlier (15–19 years) among those who do not start high school as well as in girls and women in northeast Brazil.[28,29]

Responses to closed-ended, scaled items were extracted from paper forms. Qualitative responses including personal anecdotes were transcribed in Portuguese and translated to English from audio recordings, and a content analysis was performed to guide interpretation.[30] Where applicable, qualitative responses were categorized and frequency of each response (e.g., beliefs about Zika transmission methods) was noted. A conceptual content analysis approach was used to determine categories of explicit concepts.[31,32] Respondents for whom representative quotes were extracted were arbitrarily numbered.

RESULTS AND DISCUSSION

Of 37 respondents, 89% had living children and 41% had children younger than12 years, although the respondents' ages and personal information were not recorded to ensure anonymity, given the small size of the neighborhood. Fifty-seven percent had been born in Fortaleza although only 19% reported that they were born in the neighborhood where they currently lived. No respondents declined to answer a prepared question, although the extent to which each respondent expanded on her answer was highly variable. Participants overwhelmingly responded that they were very or extremely worried about Zika (n = 29, 78%). Half of the respondents (n = 19, 51%) indicated that Zika transmission was associated with mosquitos but were not certain of how that mechanism worked (e.g., whether it was by a mosquito bite or transmitted through the air) (Table 1). Respondents perceived *Aedes*-borne diseases and their similar symptoms as common:

> *I have something with fevers. It could be Zika or dengue or chikungunya—who knows? (Respondent 31)*

> *My eight-year old son got Zika. Headaches, fever, it was pretty bad. And my aunt had chikungunya. Two uncles had chikungunya as well. My son and two of my nephews got Zika. These are common. (Respondent 2)*

Respondents also demonstrated low awareness of the Zika epidemic itself or its potential consequences for women of childbearing age (n = 10 (37%) knew Zika had more severe risks for pregnant women). One participant insisted "that disease doesn't exist here—only [in another state] (Respondent 4)" although more than 500 suspected microcephaly cases were reported for Ceará by July 2016.[33]

Participants described personal responsibility for preventing the spread of the virus, consistent with the health campaign information they reported receiving on television, the radio, and flyers:

> *You really need to keep your house clean, but also your neighbors need to be clean [to prevent Zika]. I'm not worried about Zika because I take a lot of precautions. (Respondent 14)*

The most common prevention strategy was cleaning (n = 28, 76%), consistent with the focus of public health campaigns for

TABLE 1

Frequency of common components of open-ended responses to the question "what is Zika?" from 37 women interviewed in Fortaleza, Brazil (June 2016)

What is Zika?	*n*	%
A mosquito	10	27%
A disease transmitted by mosquitos (symptoms not specified)	9	24%
A disease you can get from sexual relations	1	2.7%
A disease that causes fever or flu-like symptoms (or is similar to dengue)	8	22%
A disease that especially affects pregnant women	4	11%
A disease that affects babies	6	16%
Do not know	5	14%

the prevention of other arboviruses. For example, dengue prevention campaigns in Brazil tend to focus on education about mosquito prevention through cleaning despite evidence that investments in community sanitation are more effective.[34] In analogous community-based surveys for dengue prevention, disease knowledge is high but prevention behavior implementation is low, in part due to the lack of public health coordination.[34,35] Zika-specific prevention campaigns in 2015 and 2016 similarly focused on mosquito reduction education despite the additional risk of a secondary transmission route (sexual contact) that does not apply to other locally endemic arboviruses.[36] Few participants reported regularly using a condom to prevent Zika transmission ($n = 7$, 19%), wearing long clothing ($n = 7$, 19%) or using repellent ($n = 1$, 2%) to prevent mosquito bites (Table 2). The use of contraception of any type to avoid pregnancy, or to prevent transmission of Zika once already pregnant, was not reported as a Zika prevention strategy. When learning about sexual transmission, one respondent also commented that the perception of contraceptives among women in the community was that "these (condoms and pills) are for preventing pregnancy (Respondent 18)," not for preventing infectious disease between monogamous couples (inferred by interviewer from broader context of conversation with participant).

The average wait time for an appointment with the free, public clinic was reported as 4 months, with 76% of respondents using the free clinic as their primary means of accessing medication and treatment. Respondents reported personal dissatisfaction with their own experiences as well as a belief that services targeting women in their community were of poor quality (43% thought women's health services were of poor or very poor quality, and an additional 35% thought such services were mediocre). Furthermore, they did not feel like they had a choice other than waiting several months for an appointment with a prescriber, including for birth control other than condoms.

The health post is very close but the problem is the service is terrible. We go but then we don't get seen, or they don't have [the right medications] or something else... It's so difficult to get an appointment. People will go every day for up to a year and they are told "there are no appointments, no open appointments." I've been trying to go to the clinic to see a gynecologist [for several months]. I still haven't succeeded. (Respondent 14)

The health people never come here for family planning. Maybe one time they distributed a flyer or something but the people from the health post—I've never seen them here. (Respondent 2)

The "pill" was the most commonly known means of preventing pregnancy (51%), followed by condoms (38%), but respondents felt that women in their community would not consider getting the pill important enough to warrant paying a private pharmacy. Only two participants said they would advise a friend to go to a private pharmacy to get contraceptives.

If the neighborhood community health center doesn't have the medication you need, you just keep going to clinics in other neighborhoods until you find it. (Respondent 14)

Respondents' service priorities were more immediate than concerns about Zika virus as a potential risk. Common observations for community improvement included better management of the neighborhood by the government, improved security and infrastructure, and economic opportunity, rather than access to health services.

The consequences of Zika for pregnant women were not well known by participants at the time of the study. Less than a quarter of respondents (22%) mentioned specific risks to pregnant women or birth defects. One respondent said a mother would "go crazy" and would "have to care for him" yet did not know of any special medical services for infants with CZS (Respondent 18). Others cited "God's will" as the best recourse for the mother of an affected infant.

I know someone who has a three-month old baby with microcephaly. . . The mother didn't want to accept him. [In general] a mother would be accepting of a baby born with microcephaly and if not it's because she was lacking sufficient awareness of the [increased risk of microcephaly after Zika infection]. (Respondent 2)

Our findings are consistent with de Sousa et al.,[37] who reported that Brazilian women were afraid of the effect that Zika would have on their pregnancies but were unable to identify medical or social services to help them avoid exposure. Approaches used to reduce Zika risk in low-income Brazilian populations were unlikely to be sufficient; furthermore, having limited baseline knowledge of Zika is not enough to modify perceived risk or use of preventive behaviors.[38] In the case of our study area, limited knowledge of local Zika risk may have been compounded by poor access to primary care. The response to Zika in Brazil at the state level was restricted by insufficient funding, increasing political instability, and limited administrative capacity.[39] From the perspective of women

TABLE 2
Reported Zika-related knowledge and behaviors stratified by age of children of 37 women interviewed in Fortaleza, Brazil (June 2016)

	Has child(ren), all older than 12 years ($n = 16$)	Has child(ren), some younger than 12 years ($n = 16$)	Has no children ($n = 5$)	Total ($n = 37$)
Heard about Zika on TV	12 (75%)	16 (100%)	4 (80%)	32 (86%)
Heard about Zika on radio	12 (75%)	9 (56%)	3 (60%)	24 (75%)
Very or extremely worried about Zika	12 (75%)	14 (88%)	3 (60%)	29 (78%)
Rated own knowledge about Zika as high or very high	7 (44%)	5 (31%)	1 (20%)	13 (35%)
Protects herself from Zika using condoms	2 (13%)	4 (25%)	2 (40%)	8 (22%)
Protects herself from Zika using bednets	1 (6%)	0 (0%)	0 (0%)	1 (3%)
Protects herself from Zika using long clothes	4 (25%)	2 (13%)	1 (20%)	7 (19%)
Protects herself from Zika by cleaning	11 (69%)	14 (88%)	3 (11%)	28 (76%)

interviewed in this study, the effect of such a restrained response was a sense of business as usual regarding mosquito-borne disease and their agency to prevent it, despite knowledge of its unique risks.[1]

Limitations of this study were primarily driven by the small sample size. A social desirability effect was observed with participants giving what they perceived as "correct" answers concerning questions such as frequency of condom use. Therefore, the representativeness of our results is likely limited, given that our relatively small number of respondents (n = 37) all lived in the same neighborhood and most already had one or more children. However, the strength and direction of bias introduced relative to the level of knowledge about Zika is inestimable. The applicability of our results throughout Brazil or the rest of Latin America is unknown, but the limited resources cited and lack of Zika-specific knowledge among respondents are consistent with other studies.[6]

The qualitative and quantitative results of our study may indicate that public health educational materials, although widely available and frequently seen by the population of interest, were not sufficient to communicate the key differences between Zika and other *Aedes*-borne viruses—namely, the additional sexual mode of transmission and Zika's damaging effects during pregnancy. Although we did not directly assess the educational materials that our respondents described, 86% and 75% of respondents recalled hearing about Zika on TV and the radio, respectively (Table 2). Future research is warranted to explore culturally and linguistically appropriate means of conveying messages related to the use of contraceptives, use of condoms during pregnancy, and mosquito avoidance tactics, as well as to appropriately moderate perceived concern among women at the greatest risk for exposure.

Zika incidence has decreased in equatorial Brazil,[40–42] yet the impacts of the pandemic persist inequitably across the region. A recent analysis demonstrated that women from more impoverished communities experienced a higher burden of infants with CZS.[43] Researchers anticipate that exposure to the virus results in permanent or semi-permanent immunity,[44] reducing the potential for a near-term epidemic in populations with previous exposure. Prediction models suggest, however, that long-term risk is still present in Brazil and reemergence is likely.[45,46] Should another epidemic occur, social conditions—including poverty and poor access to health care—are unlikely to change. Further research into the fundamental social determinants of Zika infection and prevention, including condom and birth control access, is warranted in preparation of potential future transmission.

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