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Zikavírus: knowledge, perceptions, and care practices of infected pregnant women

Zika vírus: conhecimentos, percepções e práticas de cuidados de gestantes infectadas

Zika virus: conocimientos, percepciones y prácticas de cuidados de gestantes infectadas

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ABSTRACT

Objective: To understand the knowledge, perceptions and care practices of women who have contracted the Zika virus during pregnancy.

Methods: Qualitative, descriptive-exploratory study. The data collection was carried out with 10 women who contracted the Zika virus during pregnancy, through an open interview in a municipality of the Central-West Region, Brazil, in 2017. The analysis of the thematic content allowed to present two categories. The study respected the ethical aspects for research with human beings.

Results: The knowledge of infected pregnant women was reduced to little information, being the source of the information the Internet and the television, with little expression of the health services. Fear and concern about the baby are present in the feelings influencing the care practices in the gestation period.

Conclusion: Pregnant women receive little information from the health services and their prevention practices are related to the fear of transmitting the infection to the baby during pregnancy.

Keywords: Zika virus. Aedes. Infection. Pregnant women. Prenatal care. Microcephaly.

RESUMO

Objetivo: Compreender os conhecimentos, as percepções e as práticas de cuidados de mulheres que contraíram o Zika vírus na gestação.

Métodos: Estudo qualitativo, descritivo-exploratório. A coleta de dados ocorreu com10 mulheres que contraíram o Zika vírus na gestação, através de entrevista aberta, em um município da Região Centro-Oeste, Brasil, em 2017. A análise de conteúdo temática permitiu apresentar duas categorias. O estudo respeitou os aspectos éticos para as pesquisas com seres humanos.

Resultados: O conhecimento das gestantes infectadas se mostrou reduzido a poucas informações, sendo a fonte das informações a internet e a televisão, com pouca expressão dos serviços de saúde. Medo e a preocupação com o bebê estão presentes nos sentimentos, influenciando as práticas de cuidado no período da gestação.

Conclusão: As gestantes recebem poucas informações dos serviços de saúde, e suas práticas de prevenção se relacionam com o medo de transmitir a infecção para o bebê durante a gestação.

Palavras-chave: Zika vírus. Aedes. Infecção. Gestantes. Cuidado pré-natal. Microcefalia.

RESUMEN

Objetivo: Comprender los conocimientos, las percepciones y las prácticas de cuidado de las mujeres que contrajeron el Zika virus en la gestación.

Métodos: Estudio cualitativo, descriptivo-exploratorio. Se recolectaron datos de 10 mujeres que contrajeron el Zika virus en la gestación, a través de una entrevista abierta, en un municipio de la Región Centro-Oeste, Brasil, en 2017. El análisis de contenido temático permitió presentar dos categorías. El estudio respetó los aspectos éticos para las investigaciones con seres humanos.

Resultados: El conocimiento de las gestantes infectadas se mostró reducido a pocas informaciones, siendo la fuente de informaciones internet y la televisión, con poca expresión de los servicios de salud. El miedo y la preocupación con el bebé están presentes en los sentimientos, influenciando las prácticas de cuidado en el período de la gestación.

Conclusión: Las gestantes reciben poca información de los servicios de salud y sus prácticas de prevención se relacionan con el miedo de transmitir la infección al bebé durante la gestación.

Palabras clave: Virus Zika. Aedes. Infección. Mujeres embarazadas. Atención prenatal. Microcefalia.

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INTRODUCTION

An outbreak of Zika virus infections in Latin America, especially in Brazil, has caught the attention of the world population due to the hypothesis that the infection is related to damages to the gestation and to the increase of newborns with microcephaly.

The Zika virus is from the flaviviruses gender, transmitted by the mosquito *Aedes aegypti*, initially identified in monkeys in Uganda in 1947. In 1952, in Uganda and in the United Republic of Tanzania, the virus was identified in humans[1]. In Brazil, the first cases were confirmed at the beginning of 2015, in Natal, Rio Grande do Norte and Camaçari, Bahia[2-3]. Subsequently, cases were detected in the states of São Paulo, Alagoas, Maranhão, Pará and Rio de Janeiro, creating a new public health problem[4].

In November 2015, the Brazilian Ministry of Health demonstrated a possible relationship between the Zika infection and microcephaly in newborns after examinating a baby born in Ceará. Scientific research has also analyzed the issue, as an investigation in the state of Sergipe, which pointed out the existence of a transient relationship between the circulation of the virus and the occurrence of microcephaly in newborns[5].

Microcephaly consists of a malformation in which the brain does not develop properly and is characterized by a cephalic perimeter lower than what is expected for the age and sex of the baby. The Ministry of Health, guided by the World Health Organization (WHO), adopted new parameters to measure the cephalic circumference in cases of microcephaly, which is, for boys, 31.9 centimeters or less and, for girls, equal to or less than 31.5 centimeters at birth. These guidelines were used to create a standard value for all countries, considering infants born at 37 weeks or more[6].

The Zika virus infection is now listed as a national compulsory notification disease in Brazil. In the ninth edition of the epidemiological informative report on Zika, the number microcephaly cases was released. As of May 21, 2016, 7,343 cases of microcephaly were reported in Brazil, of which 1,431 were confirmed as microcephaly and/or Central Nervous System alterations[7].

Pregnant women in the first trimester of pregnancy are considered a risk population for the Zika virus infection, because it is the fetal formation phase. In the second trimester there is the risk of malformation triggered by the virus, but to a lesser degree. From the third trimester on, the risks are reduced, since the fetus is already formed[8].

The Zika virus infection can affect all age groups and both sexes. It is currently known as an acute febrile illness, which in most cases leads to a low need for hospitalization, and when the symptomatic comes with low fever, rash, arthralgia, myalgia, headache, conjunctival hyperemia and, less frequently, edema, odynophagia, dry cough and gastrointestinal disorders, mainly vomiting[9].

There is still no specific treatment for the infection, so prevention measures are the best methods to reduce cases, especially to protect against the mosquito bites[1]. The mosquito eradication and controlling the disease's propagation are the main measures to minimize the infection[10]. Therefore, the population is expected to receive education against the Zika virus from health professionals, mainly seeking the empowerment of pregnant women and their adherence to preventive measures, as well as the development of prenatal care in an effective way, since several complications can appear even during the pregnancy.

Considering the above, this research seeks to answer the following question: What are the knowledge, perceptions and care practices of women who have experienced the Zika virus infection during pregnancy? The goal was to understand the knowledge, perceptions and care practices of pregnant women who contracted the Zika virus during pregnancy.

METHODS

This is a descriptive-exploratory, qualitative approach, carried out in an important city in the mid-north region of the Mato Grosso state, in Brazil's mid-west region, with 10 women that had been infected with the Zika virus during pregnancy.

Initially, the researchers went to the Basic Health Units (BHU) of the city to verify the women notified with the infection during pregnancy. The active search for individuals was carried out by the main researcher, who went to the health units and requested the indication of infection cases by Zika virus during the gestational period. The requests were made to the nurses and to the Community Health Agents of each unit. Participants eligible for this investigation met the inclusion criteria: 1) diagnosis of Zika virus during pregnancy, regardless of the gestational trimester; 2) to reside in the local city of the study; 3) to be registered in a basic health unit of the city; 4) to be 18 years old or over; 5) to have already completed the gestational experience in which they were diagnosed with the infection. It was foreseen the exclusion of those with physical or psychological aggravations that hindered their participation in the study (however, there were no pregnant women excluded).

For the eligibility of the final number of interviewees, the criterion of data saturation was considered. This methodological resource in the qualitative research defines the mo-

ment to interrupt the construction of information according to the empirical trust that the set of interpreted information no longer provides elements for new theorization[11].

For data collection, open interviews were conducted, guided by the questions "What do you know about the Zika virus? Where or by whom did you get information about the Zika virus? Tell me about your experiences, perspectives and feelings when experiencing the Zika virus infection. What care practices do you perform against the Zika virus?" The interviews also allowed the data to characterize the participants, according to age, birth of place, schooling, occupation, family income, marital status and number of pregnancies. The interviews were conducted individually, recorded by audio (digital equipment), authorized by the participants, from March to May 2017. The place was chosen by the participant, meaning at the health unit or at their home. The field journal was also used for notes and observations made during the meetings with the women.

The analysis process of the interviews was concomitant with the collection of data, aiming to meet the data saturation criteria. All the interviews were transcribed in full and analyzed according to the technique of content analysis, thematic modality. The thematic analysis follows a path that consists of: categorization, inference, description and interpretation. From the researcher, the categorization demands great knowledge in discovering a suitable classificatory plan. The inference made when one logically deduces something from the content being analyzed. The description is defined as an enumeration of text properties, summarized after analytical treatment. The interpretation is the meaning given to those characteristics, which were enumerated during the description[12].

This investigation is a subproject of a matrix project approved by the Research Ethics Committee of the Universidade Estadual de Mato Grosso (UNEMAT) under protocol No. 1,400,656 / 2016, fully respecting resolution 466/2012. The Free and Informed Consent Term was presented to all participants of this research. They had their anonymity protected being identified by flowers names (Example: Jasmine, Orchid, Rose, among others.)

RESULTS

The socioeconomic profile of the research participants shows that they were between 18 and 36 years old; they were predominantly married, brown-skinned, with a high school education, with a monthly income of a minimum wage and born in Mato Grosso. As for parity, eight women were multiparous, with gestation numbers between one and seven, and two were primiparous. According to the research participants, no newborns presented microcephaly at birth.

After analyzing the data, two categories emerged: "The Zika virus infection associated with microcephaly: weakened knowledge of pregnant women" and "Fear, concern and care practices of pregnant women experiencing the Zika virus infection".

The Zika virus infection associated with microcephaly: weakened knowledge of pregnant women

The pregnant women expressed limited knowledge about the Zika virus infection, associating the virus with the occurrence of microcephaly in newborns, and the means of transmission by the vector *Aedes aegypt*:

> *The only thing I know is what everyone already knows, that the main problem is that it causes microcephaly in babies of pregnant women (Bromeliad).*

> *I know it gives malformation in the child, more specifically in the head. It is born with a problem, right?! And that's only the information I have (Orchid).*

> *So I know that it [the disease] is transmitted by a mosquito, the Aedes aegypt (Tulip).*

And when the counseling was offered, it came too late, offered by health professionals. The health professionals have stood out as exclusive source of professional information about the Zika infection:

> *[...], for example, in my prenatal care the doctor never told me anything [about the Zika virus] (Rose).*

> *[...] the doctor told me to put on repellent and about this kind of care at home I was not sure, I would put it on the areas that were exposed, on the clothes I did not put it, but when he told me to put it on the clothes, when this guidance came it was too late, it had already happened [the infection by the Zika virus] (Orchid)*

Regarding the other sources of information about the Zika virus, women predominantly reported the mass media among them, the Internet and their social networks and television:

> *On social networks, on TV, nowadays everywhere and anywhere we listen to they talk about it [Zika virus] (Iris).*

[...] we saw it more on television, especially in the Northeast where we watched these cases, I kept watching it, but then I stopped watching because I was scared to death [...] (Rosa).

Fear, concern and care practices of pregnant women experiencing the Zika virus infection

Pregnant women infected with the Zica virus had typical signs and symptoms of the infection, such as exanthema, itching and fever. From the clinical condition, they decided to seek the health service to perform the examination intending to discard or confirm the infection.

It started to come out several spots on my skin and itching, and until then I thought it was allergy and that I had eaten something and had reacted to it, but then I went to the doctor to take the test and Zika was confirmed (Tulipa).

[...] my body started to present little lumps and a fever, but I did not know what it was, because I had not heard much about Zika, my husband who said that I should go to the unit [BHU] that maybe it was Zika, then I started to be afraid [...] (Amaryllis).

When diagnosed, it was reported that the pregnant woman was referred to high-risk prenatal care:

[...] in the prenatal care, the doctor from our family health unit has referred us to the central unit [specialties center of the city where high risk prenatal care is performed] (Orchid).

After the diagnosis, fear and concern related to the consequences of this infection appeared, among the feelings pointed out by the pregnant women who experienced the Zika virus infection. They referred mainly to the newborn and the care that should be provided after its birth.

[...] maybe my son will come out with microcephaly, so fear dominated me the most (Tulip).

[...] fear and concern about my daughter being born with some health problem (Violet).

[...] the feeling is the worst possible, it's horrible because we do not know if it's going to happen to the baby, what's the consequence, so it's very bad (Jasmine).

[...] while you do not see its little face, you get scared (Iris).

The pregnant women also expressed the fear of not being able to take care of the child properly, if it had an alteration:

[...] fear of not being able to take care of the child if it is born with some malformation. How would I prevent it if I did not even know what that was, then I thought where I could be looking for reference, who would provide care, who would guide the mothers, all that was going through my mind (Orchid).

When I got Zika, I was scared to death, some acquaintances said: "Oh, your son is going to be born with a little head, how are you going to deal with a special person? Are you ready to be a mother, to receive such a child?", all because of Zika (Rose).

And they also demonstrated practices of care that should be adopted in preventing the Zika virus infection, such as the use of repellents, long clothing and the care that prevents the creation and proliferation of the vector:

[...] put on repellent, wear pants, be careful not to leave standing water at home (Iris).

[...] repellent, to wear long clothes, to take care of the yard, of the containers in order to avoid water for the mosquito to procreate [...] (Jasmine).

I locked the windows, until today my bedroom window is never opened, and put on repellents, I would put it on in the evening and during the day (Orchid).

The pregnant women reported not wearing long clothing due to the hot and humid weather in the city. After being infected by the virus, they did not practice the previously adopted care, such as the use of repellents:

I did not wear long clothes because I could not stand it, it's very hot, I would suffocate if I got long clothes on [laughs] (Violet).

I would put on repellent, I always took care of myself, then after I got sick I did not even care anymore! I did not put on repellents anymore, even because I felt very sick of any smell (Amaryllis).

Another aspect reported by the participants of this research was the insufficiency of the collective practices to combat breeding vectors in the community in general:

I believe that I got [infected by the Zika virus] not here at home, I think I got infected outside, because I worked and used to go out a lot. Where I worked twelve people got infected and there in the office there is a huge garden, so it may have been there (Bromeliad).

[...] here at home I never had standing water, it was always very clean. The hard thing is that there is a pasture here next to the house and the people throw everything that is dirty [...] (Violet).

DISCUSSION

The precarious knowledge of pregnant women about the Zika virus infection has already been portrayed in the literature, even in women with higher levels of schooling and income, regarding the pregnant women interviewed here[13]. The knowledge of the pregnant women who had a diagnosis of Zika virus infection, the virus in question and the symptoms that their infection causes has been reduced to little information that, to the greatest extent, are granted by the media through the Internet and television. This was also showed in another study, conducted in the United States of America (USA)[14]. This particular knowledge about the Zika infection can be seen as a weakness related to a deficit of medical and public health services guidance. This is because the participants in this study are pregnant women who performed their prenatal care at the basic health units where they were registered and, therefore, had contact with health professionals in prenatal appointments.

It is important to highlight that since the first recorded case in Brazil, in 2015, until the beginning of the data collection, in 2017, two years had already passed. In the USA, a survey was conducted on the knowledge and perceptions of women in reproductive age on the Zika virus only four weeks after the confirmation of cases of transmission originating from the country (domestic transmission) and not from people who traveled to areas at risk. The researchers found that women in reproductive age, at the Zika virus transmission sites, had much knowledge about the transmission of the disease, including being alerted by the health department to postpone pregnancies in the period. In addition, women who were pregnant knew more about the transmission than other women in reproductive age[14]. It is important to mention that, in the aforementioned study, many women (about 30%) had higher education, which differs from the educational profile of the pregnant women interviewed, who had only completed high school.

The profile of the Brazilian population that uses the public health services also deserves to be better investigated by new researches regarding the receptivity of prevention campaigns and control measures in cases of emerging diseases and outbreaks. This is because it has already been shown that particularities of the population, such as level of education, can influence how a specific population receives health information in cases of recommendation on emerging diseases prevention[15].

In Brazil, it is expected that the performance of a multiprofessional team, able to provide information to the population, can influence what the pregnant women seen in primary health services know about the Zika virus infection[8]. Although information about the disease and its conditionalities should be worked out in the BHUs, during individual prenatal appointments, or in collective educational actions, it is not possible to observe, in the statements of the pregnant women of this study, some knowledge that was beyond the relation of the Zika infection with the birth of infants with microcephaly.

Regarding the Zika virus and microcephaly relationship, Brazil presented an increase in cases of infection along with the occurrence of increased cases of microcephaly, mainly in the northeast region of the country, which was suggestive of an association between these two factors[5]. Over time, the association between microcephaly and the Zika virus infection was strengthened in the literature in 2015 and 2016[9,16]. This mix of events between increased infections and microcephaly occurred only two years before the study, which raises doubts about the ability to provide concrete statements about the Zika virus infection by health professionals, another situation which may influence the fragility of knowledge of the pregnant women studied here. The outbreak of the rapidly advancing disease from Brazil to all of America requires scientific information with strong evidence, and that this information is passed on to professionals who care for populations at risk across the Brazilian territory, generating a challenge for the government.

The lack of scientific evidence that the Zika virus infected in pregnant women is necessarily associated with microcephaly leads to a controversy in the practice of the prenatal care. The infection by the virus itself would not have serious consequences to the point where the pregnant woman needs specialized care. However, the hypothesis that this infection causes microcephaly and pathological conditions for the baby may be one of the explanations for the health professional in the basic health units to refer them to a specialized treatment, as exposed by the pregnant women interviewed in this research. This finding may indicate that fear and concern is not an exclusive feeling

of the pregnant women, but it may come from the professionals as well, who seek shelter in the search for more complex services for infected pregnant women.

The Brazilian Ministry of Health points out that the shortage of publications in Portuguese language was making it difficult for health professionals to update themselves[9]. This fact may contribute, to a certain extent, to the fragility or absence of guidance from professionals in the basic health care.

In addition to microcephaly as a consequence of the Zika infection, there are international studies published in Brazil, which show that there is a substantial risk of unfavorable infant outcomes after maternal infection[17]. A study carried out evaluating the knowledge about the Zika virus in the United Arab Emirates verified that 62.8% of the interviewees presented precarious knowledge of the disease. The study population comprised university students of medical and health sciences[18]. Thus, it is important to strengthen the discussion around the issue, not only among infected women, but also among future health professionals and academics, who are responsible for the awareness of these outbreaks and their preventive measures.

As for the knowledge source in the health units, the figure of the medical professional was present in the statements of the pregnant women interviewed for this study. This data is challenging for the National Policy of Basic Care goals, that seeks to carry out basic care with the work of a multiprofessional team. Thus, through the statements obtained here, the physician is seen as the only source of guidance, but he/she did not perform the actions of health education with a view to disease prevention. In the scope of the primary care multiprofessional team, the nurse is not present, since he/she is part of the team and performs the prenatal consultations. Nurses would be expected to be one more source of guidance on the Zika infection prevention at a time of outbreak, when being pregnant generated a number of expectations about the virus infection, which is not expressed in the present study.

Therefore, it is possible to consider the quality of the prenatal consultations regarding the dialogue to address the doubts of pregnant women about the virus infection. It should be noted that the consultations took place at a time when it was widely heard about the infection in the media, like the television, making the infection a popular subject. The response of the public health services to an outbreak, with the qualification of the professionals, as well as the receptivity of the recommendations of the Ministry of Health by the population in these cases, lacks further studies in Brazil. Recommendations from the Centers for Disease Control and Prevention in the United States indicate that, in areas of risk, every pregnant woman should be asked about the possibility of infection before and during pregnancy in every prenatal care appointment[19].

The multiprofessional health team linked to the primary health care should provide guidance to women of childbearing age who wish to have a baby about the prevention of the Zika virus infection during pregnancy. In addition, it is essential to ensure the early start of the prenatal care, as well as all laboratory and obstetric examinations and other care during consultations[9].

At the time of this study, the information campaigns promoted by the mass media contributed in a favorable way to the dissemination of knowledge. However, many media reports end up presenting the subject in a negative way, which favors speeches like the ones we collected here, expressing the feeling of fear from the information transmitted by the television. The media – the Internet and television – was also singled out as the primary source of information about the Zika virus infections in the USA in 2017, with few women receiving information from the medical services[14].

In the case of the pregnant women participating in this study, changes in the body marked the beginning of the need to seek medical care, and the Zika virus infection was not something expected by them, which can be explained by the precarious knowledge they had about the disease, including information on symptoms and prevention measures. In some people, the virus infection may be asymptomatic and when the symptoms present themselves they are usually fast and self-limited, with fever, headache, rash, red eyes and joint pain being the most frequent[1]. As the pregnant women did not know this information, they did not associate the malaise with the Zika virus infection.

In a study carried out with 60 people in four cities in the Brazilian Northeast, 100% of the individuals infected with the Zika virus presented rash, some reported as pruritus and others, even with pruritus, complained of joint pain[20]. It is important to recognize the symptoms and to offer clinical exams in the health services, seeking a diagnosis as early as possible.

Once diagnosed, the appearance of microcephaly in their baby highlights as the fear and concern experienced by the pregnant women infected with the Zika virus. The information obtained on television itself and the absence of concrete medical advice leads the population, and pregnant women, to live with the anguish, fear and concern about the infection. The findings of this study highlight the concern of pregnant women to transmit the virus to the child during pregnancy, based on the belief that the virus necessarily causes malformation and microcephaly. Concerns about the

baby have appeared much more significantly than concerns about one's own well-being. As they associate the infection with microcephaly, the fear of not being able to care for a child in this condition arises during pregnancy.

The fear of transmission to the child leads to the yearning to know how to take care of a baby with microcephaly. The pregnant women find themselves challenged as to the needs that a child with microcephaly can demand.

In the context of the infection preventive measures, it is observed the recommendation of the continuous use of long clothes, screens in windows and doors, repellents and mosquito nets. In addition to the cleaning of possible mosquito breeding sites – backyards, water boxes, potted plants, animal containers, among others. Some collective practices should be adopted by society in order to contribute to the reduction of diseases caused by *Aedes aegypti*. The best way, also pointed out by international theoretical material, is the control of the vector, which means to eliminate the mosquito. For that, it is imperative that the population eliminate all the breeding sites of the mosquito, avoiding its proliferation and spread of the disease[10].

The preventive measures taken by pregnant women during gestation were, in part, abandoned after some time. It is known, however, that reinfection by the dengue virus, in which the transmitting vector is the same, increases the chances of the disease arising in a more serious manner. This shows that part of the concern with the mosquito was due to the experience of gestation and possible infection by the Zika virus during this period.

FINAL CONSIDERATIONS

The knowledge of pregnant women regarding the Zika virus has proved to be fragile, possibly associated with the fragility of the guidelines received in appointments in basic health care units and mass media, with television and Internet being the main sources of information about the Zika virus and microcephaly. The finding referring to the high-risk prenatal care of the pregnant woman infected by Zika virus infers that there is some controversy between what is advocated for high-risk prenatal care and how these pregnant women are followed up by the professionals who attended them. In their experiences, the interviewees showed feelings like fear and concern with the infection of the newborn. They also reported care practices that should be adopted to prevent the infection by the Zika virus, however, when contracting the disease, some care practices were abandoned.

The fear and concern about the transmission to the child are important findings of this study because the literature on the Zika virus has focused on women's knowledge or adherence to prevention measures without reporting the non-biological consequences to infected women.

With the Zika virus outbreak in 2015 in Brazil, and later in the cases that spread to Central America and to the USA, scientific knowledge has increased around the viral etiology and the biological mechanism. The challenge of conducting studies that do not only raise biological and clinical aspects, but also the quality of health professionals' appointments in contact with populations at risk and cases of disease outbreak remains in Brazil.

One of the limitations faced for the development of this research was the scarcity of scientific publications regarding qualitative studies that seek the understanding of meanings and practices of women diagnosed with the Zika virus infection, since the researches that have been produced mainly translate clinical and epidemiological aspects of the infection, or studies on knowledge without association with what an infected pregnant woman experiences, such as fear and concern demonstrated in this study.

One of the contributions of this study is to subsidize primary health care professionals in understanding the knowledge, perceptions and care practices of pregnant women when experiencing the Zika virus infection. This information can provide important clues to the expansion of the clinical practice in facing the problem. Other indirect contributions of the study would be the strengthening of the debate around the theme in the scientific scenario and the improvement and amplification of the information on health practices of pregnant women and professionals aiming a better attendance of the studied population.

Further studies need to be carried out on how the population is informed and how it follows the recommendations of prevention and care in cases of outbreaks. This knowledge can bring more effectiveness to the Brazilian health system when working with populations at risk in case of new outbreaks of diseases. It is suggested that new research should be carried out, in different realities and contexts, exploring the experiences and care practices of women when they become infected by the Zika virus during pregnancy.

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