

Zika Virus: knowledge, feelings and social support network of pregnant women

Zika Vírus: conhecimentos, sentimentos e rede de apoio social de gestantes

Zika Virus: conocimientos, sentimientos y red de apoyo social para embarazadas

Thiago Gomes de Oliveira^I, Elaine Lutz Martins^{II}, Alaidistania Aparecida Ferreira^{III}, Elijane de Fátima Redivo^{IV}, Tarciso Feijó da Silva^V

Abstract: Objective: to understand the knowledge, emotions and social support network of pregnant women with clinical suspicion or positive diagnosis of Zika virus. **Method:** a descriptive study with a qualitative approach, performed with ten pregnant women. Data were collected in the second semester of 2017, through semi-structured interviews and analyzed by thematic analysis technique. **Results:** the women demonstrated a lack of knowledge about the pathology and signs and symptoms during pregnancy. Feelings of fear, despair and tearfulness are associated with the possibility of fetal repercussions when faced with a diagnostic suspicion of microcephaly. Multiprofessional care, along with family and religious beliefs were seen to offer a support network for coping with the disease. **Final considerations:** knowledge, feelings and support networks are essential when considering the policies and organization of health services, from the perspective of coping and health care.

Descriptors: Pregnant Women; Zika virus; Knowledge; Emotions; Arboviral infections

Resumo: Objetivo: compreender os conhecimentos, os sentimentos e a rede de apoio social de gestantes sob suspeita e diagnóstico positivo de Zika vírus. **Método:** estudo descritivo, com abordagem qualitativa, realizado com 10 gestantes. Os dados foram coletados no segundo semestre de 2017, por meio de entrevista semiestruturada e analisados pela técnica de análise temática. **Resultados:** evidenciou-se o déficit de conhecimento sobre a patologia na gestação e os sinais e sintomas apresentados. Sentimentos negativos como medo, desespero e choro estão associados as possibilidades de repercussão fetal frente à suspeita e diagnóstico de microcefalia do bebê. O cuidado multiprofissional, juntamente com a

^I Nurse. Master's student in Public Health from the Leonidas & Maria Deane Institute of the Oswaldo Cruz Foundation – Fiocruz Amazônia. Manaus, Amazonas State, Brazil. E-mail: thiagogomesjc@gmail.com ORCID: 0000-0003-0582-0086

^{II} Obstetric Nurse. Master's degree in Nursing. Doctoral student in Nursing, Graduate Program in Nursing, State University of Rio de Janeiro. Assistant Professor, School of Nursing, State University of Rio de Janeiro. Rio de Janeiro, Rio de Janeiro State, Brazil. E-mail: elainelutzmartins@yahoo.com.br ORCID: 0000-0002-6596-6477

^{III} Nurse. PhD in Nursing. Associate Professor, School of Nursing, Federal University of Amazonas. Manaus/Amazonas State, Brazil. E-mail: laiufam@gmail.com ORCID: 0000-0001-8553-7269

^{IV} Nurse. Master's degree in Tropical and Infectious Diseases, Graduate Program in Tropical Medicine, University of Amazonas State. Manaus, Amazonas State, Brazil. E-mail: elijaneredivo@hotmail.com ORCID: 0000-0001-8873-1032

^V Nurse. Doctor of Nursing. Assistant Professor at Estácio de Sá University – UNESA. Rio de Janeiro, Rio de Janeiro State, Brazil. E-mail: tarcisofeijo@gmail.com ORCID: 0000-0002-5623-7475

família e as crenças religiosas foram vistos como rede de apoio para o enfrentamento da doença. **Considerações finais:** o conhecimento, os sentimentos e a rede de apoio são essenciais para se pensar políticas e a própria organização dos serviços de saúde, na perspectiva do enfrentamento e do cuidado em saúde.

Descritores: Gestantes; Zika virus; Conhecimento; Emoções; Infecções por Arbovirus

Resumen: Objetivo: comprender los conocimientos, los sentimientos y la red de apoyo social para embarazadas bajo sospecha y diagnóstico positivo de Zika virus. **Método:** estudio descriptivo, con abordaje cualitativo, realizado con 10 mujeres embarazadas. Los datos fueron recolectados el segundo semestre de 2017, por medio de entrevista semi estructurada y analizados por la técnica de análisis temática. **Resultados:** se evidenció el déficit de conocimiento sobre la patología en el embarazo y los signos y síntomas. Sentimientos de miedo, desesperación y llanto están asociados a las posibilidades de repercusión fetal frente a la sospecha y diagnóstico de microcefalia del bebé. El cuidado multiprofesional, juntamente con la familia y las creencias religiosas fueron vistos como red de apoyo para el enfrentamiento de la enfermedad. **Consideraciones finales:** el conocimiento, los sentimientos y la red de apoyo son esenciales para pensar políticas y la propia organización de los servicios de salud, en la perspectiva del enfrentamiento y del cuidado en salud.

Descriptor: Mujeres embarazadas; Zika virus; Conocimiento; Emociones; Infecciones por Arbovirus

Introduction

Zika virus (ZIKV) infection is transmitted by the same vector as the dengue virus, *Aedes aegypti*. In Brazil, the first case of ZIKV infection was identified in May 2015, since when the growing number of cases and emerging evidence of an association between infection during pregnancy and the development of microcephaly have contributed to its being declared a State of Emergency by the World Health Organization. Until May 2016, 7,343 suspected cases of microcephaly were reported in Brazil, of which 1,431 were confirmed as microcephaly and/or alteration of the Central Nervous System.²

In this scenario, pregnant women have become a risk group for ZIKV infection, considering the health repercussions and fetal survival with vertical transmission. Following the epidemic outbreak of Zika virus in Brazil, many questions related to the diagnosis and conduct of professionals began to be investigated, some focusing on women of childbearing age and pregnant women, due to the impact that ZIKV infection during pregnancy can have on the health of this group and in the development of newborns.³⁻⁴

Prevention and early diagnosis of ZIKV infection in pregnant women has become an important public health policy. The differential diagnosis emerged as a challenge for health practice, due to the similarity of the viral infection of ZIKV infection with other arboviruses, such as Dengue and Chikungunya, which often hinders and delays the seeking of healthcare, and consequently, its diagnosis and treatment.⁵⁻⁶

Thus, it is believed that the situation concerning clinical suspicion and positive diagnosis of ZIKV in pregnancy has the potential to cause psycho-emotional damage in pregnant women. In addition to the innumerable changes experienced during the gestation period, a lack of knowledge about the clinical condition and possible fetal repercussions can render the pregnant woman more vulnerable.

Currently, thousands of Brazilian women face enormous uncertainty and suffering because of the Zika epidemic.⁷ In 2019, 1,649 probable cases of ZIKV illness were recorded in pregnant women, of which 447 were confirmed.⁸ In this context, negative emotional aspects are part of the maternal and family universe when the hopes and expectations of a healthy pregnancy are not fulfilled. Consequently, it can be assumed that the repercussions of ZIKV infection during pregnancy extend beyond the physical aspects of malformation in newborns.

In this sense, the need is underscored to identify strategies, such as individual or collective approaches that constitute the social support network, which aim to minimize psychological conflicts, biological changes, fears and afflictions related to infection and experience with ZIKV during pregnancy. It is noteworthy that the social support network consists of different individuals from the social sphere that provide emotional, material and educational support, resulting in emotional benefits or positive behavior.⁹

Considering the above, the importance of understanding the perception of those experiencing the process of clinical suspicion and positive diagnosis of ZIKV during pregnancy is justified, as well as the knowledge gap that negatively interferes with self-care and

comprehensive health care. In addition, this study provides an opportunity to exchange information and knowledge, while serving as a warning for the need to build care strategies for all aspects that involve the experience of ZIKV in pregnancy.

Thus, this study presents as a research question: What are the knowledge, feelings and social support networks of women experiencing Zika virus infection during pregnancy? To answer this question, the study aimed to understand the knowledge, feelings and social support network of pregnant women with clinical suspicion and positive diagnosis of Zika virus.

Method

This is a descriptive research with a qualitative approach. The study was conducted in a Basic Health Unit (UBS), in the city of Manaus / Amazonas State, Brazil. The choice of the health unit is justified by the fact that it is considered to be a reference in care for pregnant women with clinical suspicion and positive diagnosis of ZIKV infection and has a specific service for reception, screening, medical appointments, nursing consultations, psychologist support service, social work, ultrasound, obstetrics and collection for laboratory tests.

During the data collection period in the second semester of 2017, the UBS received an average of 200 pregnant women referred by the health districts of the city of Manaus, for specialized care of ZIKV infection. For the initial recruitment of pregnant women, information contained in the medical records and institutional records was evaluated. Prior telephone contact was made to invite pregnant women to participate in the research. There were clear and objective explanations of the stages of data collection in a face-to-face meeting, after prenatal consultations. Express agreement for participation was granted by signing the informed consent form.

Ten pregnant women participated in the study, three with clinical suspicion and seven with confirmed diagnosis of ZIKV infection. There was no refusal by any of them and the total

number of participants was set according to data saturation and exhaustion¹⁰, i.e., data collection continued until there was a repetition of information reported in the interviews.

It is noteworthy that pregnant women with a suspected diagnosis were also included because they had a clinical picture suggestive of infection, further strengthening the likelihood of having been infected and not diagnosed in a timely manner, due to asymptomatic or similar symptoms with other arboviruses. It is underscored that regardless of whether the pregnant women had a confirmed diagnosis of the infection; the fact that they were informed of the possibility of a positive diagnosis, and for which reason they were referred to the specialized service, probably contributed to experiencing the psycho-emotional stress related to the possibility of ZIKV infection during pregnancy.

Data collection was performed through semi-structured interviews, consisting of closed questions that allowed characterizing the participants and open questions such as: What signs/symptoms did you notice in your body that made you seek health care? What are the feelings experienced in the suspicion and positive diagnosis of ZIKV in pregnancy? Who or what do you consider to be a support network at this time of clinical suspicion and positive diagnosis of ZIKV in pregnancy? It is noteworthy that the data collection instrument was previously tested by the researcher responsible and who was trained along with the other researchers for such a research phase.

The interviews were conducted at the pregnant woman's place of choice, at home or UBS, observing aspects of sound acuity and privacy of information verbalized during data collection. The duration of the interviews was twenty to forty-five minutes. They were recorded in MP4 audio and later fully transcribed. Further, aiming at the anonymity of the participants, the transcripts of the statements were identified alphanumerically into Interview 1 (E1), Interview 2 (E2) and so on, for better presentation of the results.

Data analysis was developed using thematic analysis, observing the following steps: pre-analysis, material exploration and treatment and interpretation of results.¹¹ The pre-analysis began with a floating reading, which aimed to generate initial impressions about the material. The corpus of analysis resulted from the information obtained through the transcription of the interviews. The exploration of the material sought to codify the information, that is, the text was cut, seeking to classify these clippings into thematic categories. In turn, the treatment of results and interpretation aimed to propose inferences and advance interpretations regarding expected objectives, or concerning other unexpected findings.¹¹ After clipping, the data were classified into three main themes, resulting from grouping progressive elements, namely: knowledge of pregnant women regarding the signs and symptoms manifested by ZIKV infection; feelings about the diagnosis of Zika virus infection; and social support network for pregnant women with ZIKV.

It is noted that the research was conducted after approval by the Ethics Committee, obtaining a favorable opinion on August 4, 2017, under registration CAAE: 68817217.7.0000.5020, in accordance with all ethical aspects involving research on humans, stipulated by the National Health Council, according to resolution 466/2012.¹²

Results

The participants' age ranged from 22 to 32 years, four were single and six were married. Most (six) had completed high school and had a monthly family income of up to three minimum wages. Regarding occupation, four performed household activities, two students, an administrative assistant, a manicure and one worked in the industry sector. Furthermore, nine of the pregnant women resided in an area considered endemic for transmission of ZIKV infection.

It was found that the perception of pregnant women with clinical suspicion and positive diagnosis of ZIKV was related to: their knowledge of the signs and symptoms manifested by

ZIKV infection; feelings about the diagnosis of Zika virus infection; and the social support network for pregnant women with ZIKV.

Knowledge of pregnant women regarding the signs and symptoms manifested by ZIKV infection

Weaknesses were found in knowledge of the signs and symptoms of ZIKV, in that only one pregnant woman was able to associate the clinical signs experienced with the need to seek health services due to the possibility of ZIKV illness during pregnancy.

When I saw the red spots all over my body, the irritation in my eyes, and that weakness in my body like a fever, I immediately thought: My God I caught Zika. (E1)

The symptomatic clinical condition experienced by pregnant women with clinical suspicion and positive diagnosis of ZIKV was demonstrated by the prevalence of rashes, described by them as red spots. In addition, symptoms such as pruritus, burning eyes, fever, hand/foot arthralgia, myalgia and headache were reported, and among the least reported were diarrhea and bleeding.

It went to the spots, on the face and around here [upper limbs], on the chest and spreading. (E2)

It started with a few spots on my body and pain in my body, a lot of pain, fever and my numb finger, finger and toe, numbness only. [...] It was the whole body. Some on my face, but it was more on the body[...]. (E3)

Associated with lack of knowledge of the specific clinical picture of ZIKV, it was observed that the signs and symptoms were confused by one of the participants in this study with other pathological manifestations, such as allergies.

Well I thought that I was allergic to some medicine I was taking, that I "blistered" [blisters all over my body] then I went [...], "blistered" everywhere. (E4)

Moreover, it was seen that the possibility of ZIKV in pregnancy is something unimaginable by pregnant women and most of the time seeking health services occurred due to experiencing isolated symptoms,

I did not think about Zika because in my imagination I had the idea that this happens to the neighbor and not to me, I did not imagine that I could be pregnant and the only thing that made me seek the service was because I became all red and then I realized that something was wrong. (E5)

Feelings about diagnosing ZIKV infection

The feelings experienced by pregnant women with clinical suspicion and positive diagnosis of ZIKV were described as negative, such as fear and despair, associated with tearfulness as reported during this period. These, in turn, were linked to insecurity about a possible fetal malformation and, consequently, of the newborn being diagnosed with microcephaly.

When I took the test I went crazy, cried a lot and everything [...], I collapsed like I was very bad. Salvador has many cases of Zika, women were avoiding getting pregnant because they were afraid to catch it, in other cities in the North and the guy even talked about Manaus, I felt very bad, I cried sobbing, and my biggest fear was microcephaly. (E5)

I had a lot of doubts, it was knowing if there was a risk for microcephaly, another kind of disability, that made me very desperate. (E6)

Although pregnant women do not have enough information to relate the signs and symptoms experienced by ZIKV infection during pregnancy, some of them had already heard of the possibility of microcephaly as the main perinatal repercussion from ZIKV infection.

I was told that I could be harmed because I'm pregnant with the baby. That there were chances of him being born with microcephaly. (E1)

This pregnant woman's knowledge is explained by the extensive divulgation of information about the disease in the media that not only addresses issues related to ZIKV infection, but also covers strategies for prevention, diagnosis and treatment.

Social support network for pregnant women with ZIKV

Even in the face of shortcomings for early diagnosis due to asymptomatic conditions or symptoms associated with other arboviruses, pregnant women were satisfied with the care provided by the multidisciplinary team, which in the context of health practices sought to develop care focused on integrality and humanization.

Great, I don't have anything to complain about the service. All the professionals attended me very well. They were attentive, both in the private and public services. Attendant, doctor, nurse, psychologist, social worker they met all my expectations. (E5)

It was great; I liked the attention received by the professionals. They explained a lot to me, explained everything to me, took away all my doubts, it was very good, I liked it a lot. (E3)

It is clear from the statements that the health team's actions covered individual needs and managed to minimize some previously reported negative feelings, acting within the perspective of clarifying doubts and reassuring them about the diagnosis and treatment. Thus, health professionals became part of a social support network in the eyes of these pregnant women.

Health professionals, each result they give us, calms us down. I have also received a lot of support from the Family, which is normal. But the professionals are also supportive whenever we need it. (E4)

The pregnant women reported that this support network comprised health professionals, family and religious beliefs. It was observed that the presence of faith in the life of pregnant women with suspected and positive diagnosis of ZIKV has been remarkable and provided them purpose, resilience, comfort and hope, in order to minimize all stages of this new universe full of uncertainties and associated with negative feelings.

And move ahead and have a lot of faith in God, because right now we have to turn to God. (E2)

I understand that God sent me regardless of anything, I am a mother and I will not despise him, quite the contrary. But I have a lot of faith in God, you know, that nothing's going to happen. (E5)

Given the above, we did not identify a humanized and integral care in its entirety, which advances beyond the capacity and mastery of care techniques by professionals and which considers other needs that were presented by pregnant women in the process of clinical suspicion and coping with ZIKV in pregnancy, such as those aspects that involve spirituality.

Discussion

In 2015, ZIKV illness among pregnant women had repercussions via the media and official health agencies, which began to warn about clinical signs and symptoms that could aid in early diagnosis and treatment. Although the Ministry of Health has established protocols for the care of people with ZIKV infection and various continuing education activities in health facilities, it was observed that there still remains difficulty in reaching a diagnosis based solely on the clinical signs presented by pregnant women.

In this context, questions arose among health professionals about the process of clinical suspicion and positive diagnosis of ZIKV during pregnancy, in addition to a knowledge gap in pregnant women regarding the manifested symptoms. This problem could be explained by the clinical manifestations of ZIKV during pregnancy being confused with other arboviruses. Studies show that these symptoms are also associated with Dengue and Chikungunya, since rash, conjunctival hyperemia and temperature elevation are present in both pathologies.⁵⁻⁶

There is still no scientific evidence whether ZIKV will follow the same course as Dengue virus in Brazil, manifesting its dynamic power of hyperendemicity with all four of its serotypes infecting the population simultaneously.¹³ However, it is known that ZIKV infection presents in two forms: asymptomatic being the most prevalent; and symptomatic, where the infection is characterized by feverish episodes, maculopapular rash, arthralgia, myalgia, headache, conjunctival hyperemia, edema, odynophagia, dry cough and gastrointestinal symptoms.¹⁴

It is presumed that the difficulty in associating the clinical manifestations of ZIKV during pregnancy occurred because it is an emerging and often asymptomatic disease. Corroborating these findings, the nurses during nursing consultations do not focus on ZIKV directly, referencing only when the pregnant woman presents any signs, symptoms or complaints.⁶

When symptomatic, the main signs and symptoms that are associated with ZIKV are severe rash and conjunctival hyperemia. Physical examination becomes essential for nursing practice, identifying symptoms so that they can perform the appropriate protocol procedures.⁵ Thus, nursing care should consider the other propaedeutics for acute exanthematic infections that can also cause fetal repercussions, such as toxoplasmosis, rubella and syphilis.¹⁵

During prenatal care for pregnant women presenting exanthema with clinical suspicion or positive diagnosis of ZIKV infection, the professional responsible for consultations should have greater concern for the neurological development of the fetus. Consequently, two additional ultrasounds are recommended, one performed between the 20th and 24th gestational weeks and the other between the 32nd and 35th weeks.¹⁵

As a strategy to minimize the deficit in early diagnosis and prevention measures that are still insufficient given the severity of the disease¹, it is recommended that health professionals have knowledge and mapping of the region they attend.¹⁶ In that it is necessary to identify pregnant women early to ensure timely prevention and treatment measures are constructed and applied.¹⁶

From this perspective, holding group meetings for pregnant women is an important moment for guidance on the protection and prevention of arboviruses in pregnancy. Issues can be addressed such as: avoiding foci of the disease vector and endemic areas; using protective insect screens on windows and doors; pregnancy-specific insect repellents and condoms during sexual intercourse, since there is a possibility that ZIKV infection can be transmitted via human

semen; and also to seek health care when symptoms indicate a clinical suspicion of ZIKV illness during pregnancy.⁶

It is worth reiterating that the potential for vertical transmission between pregnant women and fetuses is a major concern and should serve as a warning in prenatal services. This is because perinatal repercussions, especially microcephaly, Guillain-Barré syndrome, brain anomalies, psychomotor sequelae and other congenital anomalies, characterize ZIKV infection in pregnant women as a public health problem.¹⁷

However, it has to be underscored that because it is a little known infection, there are many challenges faced by health professionals, especially with regard to therapy. Currently established therapy is through painkillers and anti-inflammatory drugs based on fever control and pain management.¹⁸ However, the lack of knowledge on the pathology leads to a lack of preparation to attend the pregnant woman's symptoms and complaints.⁶

This whole process of conflict and lack of knowledge in the process of clinical suspicion and positive diagnosis of ZIKV experienced during pregnancy, has abruptly and negatively reflected in the lives of pregnant women, as well as their partners, family members, health professionals and government representatives, especially in cases of congenital microcephaly.³ The impact of the birth of a child with ZIKV implies a new reality for the family, with possible impairment in the acceptance and establishment of the mother-child bond.¹⁹

In this sense, fear and despair became contradictory feelings, when facing the countless expectations and idealizations experienced in the hope for the birth of a healthy child, because what was supposed to be a moment of joy and satisfaction in the woman's life becomes moments of insecurity, distress and emotional disarray.²⁰ This antagonistic situation, characterizing the experience of ZIKV during pregnancy and, especially, in the identification of congenital diseases, causes stress and the family begins to present psychological disturbances

due to the clinical condition of the pregnant woman together with the risks that the child may present at birth.²¹

These doubts and anxieties surrounding a pregnancy threatened by ZIKV infection and their babies being born with microcephaly recurrent in arbovirus occurs due to mass dissemination through the media regarding the ZIKV outbreak, such that most pregnant women have categorically related microcephaly with the infection. Corroborating the findings of this study, microcephaly was the complication most reported by nurses, since they are aware that it leads to impairment of the fetus and, consequently, the newborn.⁶

Based on these perceptions, it is known that Brazil was the first country to identify a possible relationship between ZIKV infection in pregnancy and the occurrence of microcephaly in newborns (NB). Among the first 35 cases of NB with microcephaly reported in eight states of the Country, in August and October 2015, 71% of NB had severe microcephaly (head circumference with more than three standard deviations below the mean for age and sex), 49% had a neurological abnormality, and all 27 newborns that underwent neuroimaging examinations presented abnormalities.²²

With the diagnosis of microcephaly, the family begins to experience feelings of uncertainty, which will only be defined, more precisely, by each individual coping with the deficiencies that will be presented by the child. These feelings experienced by parents constitute a form of conflict, because they are faced with an unexpected situation through which they lost their idealization of the child they had dreamed of.²³

Thus, comparing the findings in this study, it is found that some feelings presented by pregnant women with ZIKV are repeated, notably fear, anxiety and worry.²⁴ It is noticed that the negative feelings reported by pregnant women have a strong relationship with the lack of information about Zika virus.²⁰ Furthermore, feelings of anguish and uncertainty were also

experienced by parents at the moment they were informed of the diagnosis that a baby with microcephaly would be born into their family.²³

In addition to feelings of fear and anxiety, shock and denial are also common in the face of confirmation and diagnosis of the disease. It is characterized as a delicate and difficult moment for the entire family of the pregnant woman, since it raises the possibility of congenital malformation.²¹ In this context of negative perceptions and doubts about the consequences of the experience of ZIKV during pregnancy, the importance of multiprofessional team performance is highlighted. This demands a very well-structured social support network and a team of health professionals, capable of supporting not only the pregnant woman, but also her family in order to face and adapt to their new reality.²³

Corroborating these findings, the perception of pregnant women regarding the formation of a support network was demonstrated by their satisfaction in the attendance and reception during health care and family support. It is considered that such satisfaction in care is a reflection of the interaction of the multidisciplinary team and, specifically, the performance of the nursing team, through proximity to the patient, and may develop a holistic outlook that contemplates, in the process of care, the biological, mental, emotional dimensions, and spirituality of the Human being.²³

Thus, the health team must be prepared to welcome the pregnant woman and develop active and qualified listening, without judgment or prejudice, allowing them to express themselves freely. Accordingly, it becomes apparent that it is necessary to use pregnancy care as a health surveillance strategy for the production of care²⁵ and networking with the development of actions involving various sectors.

Regarding spiritual support, whether by religion, professionals, or family members, despite being present in health discourses is something that appears to be very fragile in professional practice.¹⁸ Nevertheless, it offers health benefits, as is the case with pregnant

women with clinical suspicion and confirmed diagnosis of Zika, by minimizing the fears and anxieties experienced during this period.

Thus, the importance is evident of considering the various cultural factors in the practice of nursing, since spirituality is one of these elements, and incorporating this aspect into care can become a relevant tool in the process of coping among pregnant women facing the possibility of giving birth to a child with a malformation.²⁰

Final Considerations

Prior knowledge regarding ZIKV infection from the perspective of pregnant women with suspected or positive diagnosis is still limited. Usually, the signs and symptoms manifested were not associated with the possibility of Zika infection, except for the consequences such as microcephaly. This congenital anomaly is one of the main fears voiced by the pregnant women.

To meet the negative feelings experienced in this process of clinical suspicion and positive diagnosis of ZIKV during pregnancy, pregnant women recognize a social support network comprising the multiprofessional team, family support and religious beliefs. Despite the challenges faced by health professionals and pregnant women themselves in identifying the specific signs and symptoms of ZIKV infection rather than with other arboviruses, holistic care is essential to minimize eventual psycho-emotional harm experienced during this period.

In this sense, the importance of continuing education among health professionals is emphasized for the control and clinical management of pregnant women affected with ZIKV and, consequently, comprehensive and humanized care in the pregnancy-puerperal period. Furthermore, health education activities during pregnancy with groups of pregnant women are essential strategies for the exchange of knowledge, which is essential for women's empowerment and self-care throughout their pregnancy.

Finally, it is noteworthy that this study presented as a limitation the difficulty of defining the positive diagnosis of ZIKV in pregnancy, due to the asymptomatic or situation similar to

other arboviruses in the participants. The inclusion of pregnant women with suspicion, even though it did not make the results unfeasible, was carefully evaluated, considering the magnitude of the infection during pregnancy, in that it certainly provoked similar feelings such as fear and insecurity in pregnant women whether with clinical suspicion or positive diagnosis of ZIKV.

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Corresponding author

Thiago Gomes de Oliveira

E-mail: thiagogomesjc@gmail.com

Address: Rua Abraão Cardoso, nº18, Compensa I, Manaus, Amazonas, Brazil.

CEP: 69036-000

Contributions of authors

1 – Thiago Gomes de Oliveira

Contributions in the phases of conception, planning, data collecting, analysis and interpretation, redaction and critical revision.

2 – Elaine Lutz Martins

Contributions in the phases of conception, planning, data collecting, analysis and interpretation, redaction and critical revision.

3 – Alaidistania Aparecida Ferreira

Contributions in the phases of conception, planning, data collecting, analysis and interpretation, and redaction.

3 – Elijane de Fátima Redivo

Contributions in the phases of data interpretation, redaction and critical revision.

4 – Tarciso Feijó da Silva

Contributions in the phases of data interpretation, redaction and critical revision.

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