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Suspected pregnancy and diagnosis of Zika virus infection

Embarazo con sospecha/diagnóstico de infección por el virus del Zika

Gestação com suspeita/diagnóstico de infecção pelo Zika Vírus

ABSTRACT

This is a qualitative study, using semi-structured interviews as a data collection instrument. Data saturation was due to the wealth of data, proceeding to content analysis, in the form of thematic analysis. Four pregnant women were interviewed, a puerperal woman and a spouse. After analysis, two thematic categories were identified, namely: knowledge about the Zika Virus and its complications; and repercussions and daily support in pregnancy with suspected or diagnosed Zika virus. The knowledge mobilized by the people who experience the disease emphasized the structural aspect of the baby's head, which pointed to concern with the issue of disability and physical appearance. The repercussions on the daily life of the pregnant woman and her surroundings promoted the reorganization of social bonds, reaching dimensions of private life, with emphasis on the socioeconomic dimension and spirituality. The experience in the face of this situation had repercussions on family projections and plans, on the rhythm of moral issues that sediment actions and choices in the public and private sphere.

DESCRIPTORS: Pregnancy Complications; Zika Virus; Microcephaly.

RESUMEN

Este es un estudio cualitativo, que utiliza entrevistas semiestructuradas como instrumento de recopilación de datos. La saturación de datos se debió a la gran cantidad de datos, que procedió al análisis de contenido, en forma de análisis temático. Se entrevistó a cuatro mujeres embarazadas, una mujer puerperal y un cónyuge. Después del análisis, se identificaron dos categorías temáticas, a saber: conocimiento sobre el virus del Zika y sus complicaciones; y repercusiones y apoyo diario en el embarazo con el virus Zika sospechado o diagnosticado. El conocimiento movilizado por las personas que experimentan la enfermedad enfatizó el aspecto estructural de la cabeza del bebé, lo que señaló la preocupación por el problema de la discapacidad y la apariencia física. Las repercusiones en la vida cotidiana de la mujer embarazada y su entorno promovieron la reorganización de los lazos sociales, alcanzando dimensiones de la vida privada, con énfasis en la dimensión socioeconómica y la espiritualidad. La experiencia frente a esta situación tuvo repercusiones en las proyecciones y planes familiares, en el ritmo de los problemas morales que sedimentan las acciones y elecciones en la esfera pública y privada.

DESCRIPTORES: Complicaciones del Embarazo; Zika Virus; Microcefalia.

RESUMO

Trata-se de estudo qualitativo, utilizando como instrumento de coleta de dados entrevista semiestruturada. A saturação dos dados se deu pela riqueza dos dados, procedendo a análise de conteúdo, na modalidade da análise temática. Foram entrevistadas 04 gestantes, uma puérpera e um cônjuge. Após análise, foram identificadas duas categorias temáticas, sendo elas: os saberes sobre o Zika Vírus e suas complicações; e repercussões e apoios cotidianos na gestação com suspeita ou diagnóstico de Zika Vírus. O saber mobilizado pelas pessoas que vivenciam o agravo enfatizou o aspecto estrutural da cabeça do bebê, que apontou preocupação com a questão da deficiência e da aparência física. As repercussões no cotidiano da gestante e do seu entorno promoveram a reorganização dos vínculos sociais, alcançando dimensões da vida privada, com destaque para dimensão socioeconômica e espiritualidade. A experiência diante dessa situação se repercutiu nas projeções e nos planos familiares, no compasso de questões morais que sedimentam as ações e as escolhas na esfera pública e privada.

DESCRITORES: Complicações na Gravidez; Zika Vírus; Microcefalia.

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INTRODUCTION

In November 2015, the Ministry of Health brought an alert about the relationship between Zika Virus (ZIKV) infection in pregnant women and the birth of newborns with microcephaly in Brazilian territory, and the existence of this association was later confirmed by the World Health Organization and the United States Centers for Disease Control and Prevention(1-3).

Transmission of ZIKV can occur through the vector mosquito Aedes aegypti, but also through blood transfusion and sexual intercourse(3). Microcephaly has become one of the best known clinical forms of congenital infection in newborns, however, there are other clinical manifestations encompassed by the Zika Virus Congenital Syndrome - SCZV(4,5), due to its ability to reach the central nervous system, affecting fetal growth and development, and causing physical, neuromotor and cognitive changes(4,6).

SCZV is considered a chronic condition that directly affects the family, requiring parents to have frequent contact with health professionals and services and the need for permanent care of the affected child. Microcephaly and ZIKV infection can be diagnosed during pregnancy, generating apprehension and uncertainty on the part of the family regarding the suspicion or diagnosis, especially of the parents(7), because, for many cases, treatment is unpredictable or inaccessible. Therefore, it is considered relevant to understand the experience of pregnant women with suspected or diagnosed ZIKV due to the need for a more sensitive look at the singularities and subjectivities involved in its consequences.

In this scenario, valuing the subjective aspects of those who feel such events on the skin (pregnant women, spouses), can provoke reflections on care, daily life, and the meanings of assistance in the face of this chronic condition. Experience is understood as the result of multiple experiences condensed into particular meanings and that express some meaning for the person who experienced it, being permeated, however, by objective elements(8). If meanings are involved, it presupposes interpretation, in which the subjects have a stock of prior knowledge(9). Experience is what reveals the way of being in the world and the means by which the world is placed in our face and within us(10), also referring to "the means by which individuals and social groups respond to a given episode of illness"(11).

It was proposed to understand some aspects of the experience of pregnant women, puerperal women, and spouses in the face of the suspicion or diagnosis of ZIKV, seen at a reference service in the State of Mato Grosso, Brazil. The following guiding questions emerged: What is the knowledge mobilized by pregnant women, puerperal women, and spouses about ZIKV during pregnancy? What are the repercussions of this problem in everyday life? And what support possibilities have emerged?

METHODOLOGY

This is a qualitative study conducted in a reference service for outpatient care and hospitalization of pregnant women with suspected or diagnosed ZIKV, between the months of January and June 2018, which was duly approved by the Research Ethics Committee with human beings, under opinion No. 1.842.018 and CAAE: 59553716.9.0000.5541.

The selection of participants was intentional, through personal invitation during technical visits to the location selected for the research. Inclusion criteria were being over 18 and receiving care at the health service related to the suspicion or diagnosis of ZIKV infection during pregnancy. The number of participants was delimited based on the wealth of data collected in the interviews. According to Minayo(12), an ideal qualitative sample is one that reflects, in quantity and intensity "the multiple dimensions of a given phenomenon". In all, there were 06 research participants: four pregnant women, a puerperal woman and a spouse, which in the excerpts of speeches brought are identified by the P code for pregnant women, followed by random numbering (P1, P2, P3 and P4), Puerperal and Partner , respectively.

About the data production, an interview was conducted with a semi-structured script and the content analysis, in the form of thematic analysis, guided its treatment(13). The discussions were organized into two thematic categories: Knowledge about the Zika Virus and its complications and Repercussions and daily support in pregnancy with suspected or diagnosed Zika Virus.

RESULTS

All pregnant women were married, aged between 22 and 32 years, during the interview period the gestational age varied between 23 to 39 weeks, three of them were hospitalized with suspected ZIKV and had comorbidities, such as: gestational diabetes, hypertension, pneumonia and anemia. None of them was accompanied by their spouse during hospitalization. Two participants were selected while waiting for assistance in the outpatient service screening sector. One of them was interviewed after receiving a positive ZIKV laboratory test and was accompanied by her 32-year-old husband, who also participated in the research. The puerperal woman, on the second postpartum day, was hospitalized without a companion and the newborn was in the Neonatal Intensive Care Unit, diagnosed with microcephaly by ZIKV.

The experience of women with suspicion and diagnosis of ZIKV infection proved to be a sensitive phenomenon to the body, having an important role in its design, as a way of living / being in the world(10,14). This is because it is in the body that the signs of illness are evident and it is in it that the daily interventions are focused, be it prevention, diagnosis, and care of the disease.

Among the bodily manifestations of symptoms of ZIKV infection, cited:

> *"Joint pain, muscle pain, headache, fever, nausea, dizziness, itchiness, like, for me it was scabies, it looked like scabies, it was very thick [the skin]." (P2).*

> *"Swelling in the joints and ankles, in the hands, the very reddish body is [...] still swollen [...] the spots are not gone and fever, high fever [...] was 39º fever and a lot of pain head, body pain" (P4).*

In addition to the body, the subjective aspects brought the knowledge mobilized by the experience in the face of the suspicion or diagnosis of ZIKV infection, which is presented below.

Knowledge about the Zika Virus and its possible consequences in pregnancy

The experience has both subjective and intersubjective aspects, which presuppose the existence of frames of reference - internalized by the subjects through concrete processes of social interaction(11), which mobilize the most varied knowledge that circulate in the social environment, including those about the ZIKV and microcephaly.

To Schutz(9), what a person knows in his daily life "is anything he thinks is knowledge", which concerns practical issues, constituting his stock of knowledge. In the experience of falling ill, feeling bad or feeling that something unexpected can happen - such as the birth of a baby with microcephaly - sets knowledge and the ability to transform this experience into knowledge in motion(11).

> *"What I do know is that the baby can be born with malformation [...] I know that the child is born with a small head" (P4).*

> *"[...] he [ZIKV] destroys something in the baby's head and then he can be born with microcephaly" (Puerperal).*

> *"I know that he [the ZIKV], when we are infected, he can give the child microcephaly at the beginning of pregnancy [...] I'm not sure if this happens in the middle to the end, but yes, in the beginning of pregnancy cause this disease [...]" (P2).*

The statements can reveal that the knowledge mobilized by the people who experience the disease emphasizes the structural aspect of the baby's head - size, deformity - which points to the concern with the disability and appearance. In this sense, the practical and daily knowledge of each person can serve as an interpretive scheme of past, present experiences and even anticipating occasions to come, such as the birth of a child with microcephaly.

In matters involving physical disabilities, especially those that are more visible and identifiable (embodied in appearance), as in the case of microcephaly, knowledge can denounce the difference(15) when relating to stigma - which refers to a derogatory attribute and which can manifest itself in the language of relationships (16), showing a characteristic different from that which is predicted as a social norm ("a healthy baby").

In fact, microcephaly is the most well-known clinical manifestation among the interviewees and, also, the most socially propagated. However, it is important to remember that it is one of the clinical forms of SCZV, which can take on the most diverse manifestations and changes(5).

In daily life there are several means of dissemination and information about ZIKV and microcephaly, such as: the social network, official prevention campaigns, guidelines provided by health professionals in prenatal care, as well as through social interaction with people from their surroundings (family, neighbors, colleagues, community, etc.); thus constituting important matrices of meanings and practices (references), where previous experiences are sedimented and organized as knowledge by hand(9), easily accessed and interpreted.

The knowledge mobilized (available) in daily life circulates / propagates dynamically in society and is diversely appropriated by the subjects, who are culturally constructed, elaborated and articulated(17), as in the news and on the television media:

> *"Then, suddenly, you know that your wife has this Zika virus [...] you already know on television what causes" (Partner).*

> *"I do not know much. I just saw what was on TV, right? At that time there was an outbreak. Then, I saw it, but I never went deeper [...] I only saw the issue of microcephaly" (P1).*

It was noted that the media was present in everyday life and that its media connections could be useful to bring information, (re) produce and share socio-cultural meanings in the face of the problem. In addition to transmitting symbolic content, the media can also influence the formation of political and social thinking(18), however, such a process is not something mechanical and passive, as it is necessary to consider people's capacity in the (re) elaboration and (re) integration of knowledge for the composition of the knowledge stock.

So, "even the most stereotyped cultural ideas exist only in the minds of the individuals who absorb them, and who interpret them based on their own life situations"(9), giving them a personal and singular record. In other words, people do not exclusively use specific information about ZIKV and microcephaly provided by popular and / or scientific media, due to the possibility of contributing to knowledge / ideas about other conditions that affect the body (physically and mentally), which were previously transmitted and that are updated and reframed in the daily situation that presents them.

Thus, in different situations in the world of life, people can be led to reflection and interpretations in sociocultural contexts shared with others - intersubjective world(14). In a practical way, with regard to women's body care, knowledge about the ways of transmission of ZIKV are also important to think about more effective measures for the prevention of the disease(19) and that are more consistent with reality.

The testimonies revealed a greater emphasis on the transmission of the virus by vector mosquitoes and on the adoption of control measures over the environment that are more widely disseminated in the media:

> *"[they said] it was for me to use repellent, it was for me to avoid dark clothes [...] cleaning my house, not leaving water, tire like this, water in the tire, these things [...]" (Puerperal).*

> *"At home we don't leave any standing water, always taking care, understand? Screen [anti mosquito] [...] she [the pregnant woman] passing her protector too - the repellents [...]" (Partner).*

However, another testimony reproduced less disseminated elements of biomedical knowledge:

> *"[the ZIKV is] contracted by the mosquito or sexually transmitted" (P2).*

Such knowledge is supported by official individualizing campaigns about what women are expected to do throughout the gestation period, whether through protective measures, anti-mosquito (topical repellents, clothes with less skin exposure, domestic fabrics, etc. .), or through the use of condoms during sexual intercourse(19). These are anchored in the biomedical knowledge matrix that strongly supports prenatal care in health services and that has guided the elaboration of care manuals and protocols for health professionals.

> *"[...] since I found out [ZIKV's suspicion] I was doing follow-up, it was fortnightly [...] After the eighth month, it started to be weekly because she [the baby] was not developing and we are watching to see if it is because of the virus."(P3).*

Rapid advances in technologies for the prenatal diagnosis of fetal diseases and malformations have been accompanied by the shift in the identification of deficiencies and specific conditions through morphofunctional calculations and risk control, blurring its borders in the private sphere. For example, in severe congenital disorders, which includes SCZV, the options for choosing women seem to be very restricted, as the possibility of terminating the pregnancy by own decision is permeated by moral and bureaucratic-legal elements(20).

In this sense, the scrutiny of fetuses and scientific knowledge, even if necessary from a biomedical perspective, may become useless in the face of the lack of treatment that can interfere with the abnormal development of the fetal brain and the legal-legal impossibility of choosing women for interruption of pregnancy in Brazil(20). So, it is questioned what is the use of prenatal diagnosis in addition to the stress of women and family and the considerable consumption of biotechnological procedures costly to the health system (whether public or private)?

In the next topic, issues that involve the repercussions of this problem in the daily life of pregnant women and their families are highlighted, understanding what are the possible sources of support that have emerged composing the experience.

Repercussions and daily support in pregnancy with suspected or diagnosed Zika Virus

The feelings reported by the participants are among the most immediate repercussions generated by the suspicion or confirmation of the diagnosis of ZIKV during pregnancy, which include fear, frustration, uncertainties, and emotional conflicts:

> *"I came here to get the test result, I'm scared" (P4).*

> *"I was desperate, I cried, I thought a lot about why this happened, I was really sad, I was very upset" (Partner).*

> *"Cry. I cried a lot even before doing the ultrasound because she [baby] was not developing, she was not gaining weight and she was also not in the proper size. I was very worried, right [...] I was even having trouble sleeping" (P3).*

Note the intermediation of repercussions by diagnostic technologies and on this aspect, the reflections of the Sociology of Diagnosis can provide important elements to this discussion by bringing the diagnosis as a category, process and consequence(21). The intrauterine diagnosis of microcephaly is therefore mediated twice by examining the woman's body and the fetus(20), that have a different impact (consequences) on everyone involved(21,22) - pregnant women, spouses, family, etc.

> *"[...] even to sleep, I lie in bed and [...] I think, will my daughter be born with a health problem, with a defect? [...] I was desperate [...] on the same day I took him to the doctor, we know it was Zika, we came to the hospital, we already did tests, we went to the doctor, we did ultrasound, they measured to see how the shape of the child [...]" (Partner).*

Considering the situation of pregnant women and family members in relation to diagnostic procedures allows to approach the diagnosis as an act, an interpretative process, which unfolds in emotions, knowledge and interactions, in particular, with health services and professionals, producing effects that have repercussions. far beyond the hospital and / or doctor's office(21) to spread out in family interactions and arrangements by focusing on your future plans and projects.

However, the expectations and life plans of the affected families can be reconfigured in the long term, through renegotiations, decisions and initiatives that cover different areas of life(8) and resizing future projects(17). After the suspicion / diagnosis of the condition, there were changes in the family routine, especially for the pregnant woman, requiring more time and dedication during prenatal care, which sometimes led to leaving aside other daily activities, such as home, studies, work and leisure(7).

> *"[...] now I will have to do an ultrasound a week to accompany the baby. By symptoms and diabetes [...]" (P2).*

> *"[...] all of a sudden, it turns people's lives around, but it is a child that is being born, it is your child that is being born" (Patner).*

In addition to the routine imposed by the pregnancy itself, a period of significant changes, it is added that the family is required to mobilize and reorganize, even more, to meet the needs generated by this unusual circumstance. The new demands can stimulate the rearrangement of bonds and routine activities of each family member(23), as evidenced:

> *"She [the wife] is going to the health center near the house several times, but I work [...] there, my father searches or my brother [...]. Here at the Hospital it is a bit distant and I have to accompany her too, because here I don't know what time it will end, it takes" (Partner).*

Family action is essential in this situation, especially when plans for pregnancy are compromised during the uncertainties of fetal / child development, family support can be activated according to the circumstances of life and daily needs. In this way, the family can become a stable element that would allow people to find meaning in their actions(24). However, the expectations generated around the family must be considered as possibilities in sight and not concrete guarantees. Family support is not unconditional and absolute, as it depends on the socio-cultural context in which it is inserted(25).

In this context, family support could reinforce the potential with an important participation: the strengthening of solidarity bonds(24) – that plays a fundamental role in the provision of individual needs and in the provision of various care throughout the life cycle, such as from pregnancy to the child's growth / development, in which each family member would become an active node / nodes in the provision of care and in maintaining everyday life(26).

> *"[...] he [the husband] started to monitor more in the prenatal period, a little more attention than before" (P3).*

> *"he [the husband] gives support [...] [I receive] support from my*

> *mother [...]. I've been talking a lot with my mother, every day I talk to her" (P4).*

The testimonies showed that, when there is a concern or need during pregnancy, closest people can become involved with the situation / problem becoming an essential part of the support network - the strongest and most active nodes in the bonds of solidarity(24,26). However, this fact is not a social norm, on the contrary, as some studies have pointed out abandonment and the lack of family ties(25,27). So, the influence of the social network can be shown both positively and negatively(24).

When they act positively, support networks can be defined by the availability of support based on significant social bonds(24), as in the case of the pregnant woman's spouses and family members, in the face of crisis situations, doubts and concerns, providing coping strategies through encouragement or care, especially in periods of transition and major changes(28).

After the birth of a child with a disability and / or congenital malformation, as in the example of SCZV, changes in the routine, dynamics and family structure continue to occur, including the financial costs required for continuous care, coming / going from specific consultations / exams and specialized services, as well as the constant need for access to health services(23), not always covered by specific health plans, inputs / products (food, hygiene, etc.) and, equally, not covered or subsidized by the health system. As pointed out by a pregnant woman:

> *"[...] it starts with diapers, clothes, accessories, milk [...]. All of this has an expense [...] We first wanted to build a house [...] And a child is a built house, right?" (P2).*

Reports as evidenced a certain economic vulnerability of these families that, potentially, can be amplified by the occurrence of a chronic condition. The most diverse social needs require support and better management of financial resources, as well as the establishment of priorities for the allocation of these resources, which may, depending on the financial conditions of each family, modify future individual / collective projects(18,22,23).

> *"I had a plan to go to college next year. I'll do it, but now it will take longer" (P2).*

There were different sources of social support for pregnant women and their families who received the news of the suspicion / diagnosis of ZIKV infection, which helped them in this critical phase(28). One of these sources was faith:

> *"But we have faith in God that everything will be all right [...] In my heart, the way God sends it to me will be welcome" (Partner).*

> *"Everyone [in the family] praying to be all right" (G3).*

Faith can be understood as a manifestation of spirituality that provides hope, comfort and well-being, in an attempt to overcome the adversities generated by the news, helping to accept and minimizing suffering and anxiety(6,7). Nevertheless, it is necessary to consider the moral issues that permeate being a woman and being a mother, demanding a conduct of devotion and mission that is almost inescapable:

> *"God never gives us a burden, that we cannot carry [...] it would certainly have to be adapted, because a mother is a mother, right? Mother does not matter. The child can come without the leg, without the arm, without hair, naked, in any way [...] We accept the same way" (P2).*

On the adjacent moral issues, Löwy(20) it critically points out the weight that falls, above all, to women when assuming the consequences of the birth of their children and of the respective permanent and progressively worsened care, depending on the degree of dependence - whose prognosis is admittedly inaccurate. Thus, men and women, to an unequal extent, answer the moral questions that are involved in the experience of taking care of their children, however, the biographical trajectories are sensitive to the contexts in which they are inserted and are expressed in different ways, being driven by a set of cultural codes of the various matrices of meanings(18), among them, the religious matrix - traditional and extremely fertile for understanding the experience on screen.

FINAL CONSIDERATIONS

Understanding the experience of pregnant women with suspected / diagnosed ZIKV implied recognizing and valuing the subjective aspects that marked the trajectory of lives, the knowledge mobilized and the contexts, to broaden the look on their reality and, potentially, to act in a different way, more sensitive, considering socio-cultural aspects.

The experience revealed significant changes in the daily life of the pregnant woman and those around her, promoting the reorganization of social bonds and reaching dimensions of private life, with emphasis on the socioeconomic dimension and spirituality. In addition, it had repercussions on family projections and plans, on the compass of moral issues that sedimented actions and choices in the public and private sphere.

In this sense, the repercussions were revealed in the intertwining of material and immaterial / symbolic, clinical and social elements, in a dynamic and striking way, reaching people in their surroundings (family members, health professionals, etc.) in the fabric of social support networks. However, social support should not be provided only by people and their relationships, weighing heavily on the individualization and accountability of the family in social welfare(25), but primarily as a result of the responsibility of the welfare state for the legal-legal apparatus, public policies, the system of resources and social services, in response to a public health problem.

The affects generated by the repercussions / impacts add up and, at times, are confused with other social issues, intermingling. So, expanding the context studied to include structural aspects (class, gender, social policies, etc.) by understanding the experience of families affected by ZIKV is still essential.

Therefore, the understanding of the studied phenomenon is not exhausted, nor can it be taken for granted. It is necessary to explore and analyze it in different socio-cultural contexts from different points of view of the subjects involved. Anyway, it is hoped that the reflections brought may instigate other studies of this nature involving the present theme, especially in the socio-anthropological aspect, which has contributed a lot in health research. ■

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