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CONGENITAL ZIKA VIRUS SYNDROME: KNOWLEDGE AND HOW TO COMMUNICATE THE DIAGNOSIS

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ABSTRACT

Objective: to know how mothers affected by the Zika virus during pregnancy became aware on the diagnosis of Congenital Zika Virus Syndrome in their child and to understand the way in which the communication of the diagnosis was transmitted.
Method: a qualitative approach study, with interpretative research, based on the Resilience, Stress, Adjustment and Family Adaptation Model. The research was conducted in a Specialized Rehabilitation Center in a city of Paraíba (Brazil), from June to November 2017, with 40 mothers of children with congenital Zika virus syndrome. The empirical material was produced from a semi-structured script developed by the researcher, related to the different phases and components of the adaptation and resilience process. The findings were submitted to content analysis.
Results: two thematic categories were unveiled: The discovery of Congenital Zika Virus Syndrome: period of diagnosis and maternal expectations, and How to communicate the diagnosis: implications for the discovery of Congenital Zika Virus Syndrome.
Conclusion: Communication of the diagnosis and professional conduct at the time of information play important roles in re-signifying the meaning of congenital malformation. The interaction established by the health professional and their posture are directly related to the satisfaction about the information received.

DESCRIPTORS: Women's health. Zika virus. Microcephalus. Diagnosis. Epidemics.

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SÍNDROME CONGÊNITA DO ZIKA VÍRUS: CONHECIMENTO E FORMA DA COMUNICAÇÃO DO DIAGNÓSTICO

RESUMO

Objetivo: conhecer como as mães acometidas pelo Zika vírus na gestação souberam do diagnóstico da Síndrome Congênita do Zika vírus em seu(sua) filho(a) e apreender a forma com que a comunicação do diagnóstico foi transmitida.
Método: estudo de abordagem qualitativa, com investigação interpretativa, fundamentado no Modelo de Resiliência, Estresse, Ajustamento e Adaptação Familiar. A pesquisa foi realizada em um Centro Especializado em Reabilitação de um município da Paraíba (Brasil), no período de junho a novembro de 2017, com 40 mães de crianças com a Síndrome Congênita do Zika vírus. O material empírico foi produzido a partir de um roteiro com caráter semiestruturado desenvolvido pela pesquisadora, relacionado com as diferentes fases e componentes do processo de adaptação e resiliência. Os achados foram submetidos à analise de conteúdo.
Resultados: foram desveladas duas categorias temáticas: A descoberta da Síndrome Congênita do Zika vírus: período do diagnóstico e expectativas maternas, e A forma da comunicação do diagnóstico: implicações diante da descoberta da Síndrome Congênita do Zika vírus.
Conclusão: a comunicação do diagnóstico e a conduta profissional no momento da informação possuem papéis importantes na ressignificação do sentido da malformação congênita. A interação estabelecida pelo profissional de saúde e sua postura estão diretamente relacionadas com a satisfação sobre a informação recebida.

DESCRITORES: Saúde das mulheres. Zika vírus. Microcefalia. Diagnóstico. Epidemias.

SÍNDROME CONGÉNITO DEL VIRUS DEL ZIKA: CONOCIMIENTOS Y CÓMO COMUNICAR EL DIAGNÓSTICO

RESUMEN

Objetivos: conocer de qué manera las madres afectadas por el virus del Zika se enteraron del diagnóstico del Síndrome Congénito del Virus del Zika en sus hijos, y determinar cómo se comunicó el diagnóstico.
Método: estudio de enfoque cualitativo, con investigación interpretativa, fundamentado en el Modelo de Resiliencia, Estrés, Ajustes y Adaptación Familiar. La investigación se realizó en un Centro Especializado en Rehabilitación de un municipio da Paraíba (Brasil) entre junio y noviembre de 2017 con 40 madres de niños con el Síndrome Congénito del Virus del Zika. El material empírico se produjo a partir de un guión con carácter semiestructurado desarrollado por la investigadora, relacionado con las diferentes fases y componentes del proceso de adaptación y resiliencia. Los hallazgos se sometieron a análisis de contenido.
Resultados: surgieron dos categorías temáticas: La detección del Síndrome Congénito del Virus del Zika: período del diagnóstico y expectativas maternas, y Cómo comunicar el diagnóstico: implicancias al momento de detectar el Síndrome Congénito del Virus del Zika.
Conclusión: comunicar el diagnóstico y la conducta profesional al momento de dar la noticia tienen un peso importante en la resignificación del sentido de la malformación congénita. La interacción que establece el profesional de la salud y su postura están directamente relacionadas con el nivel de satisfacción con respecto a la información recibida.

DESCRIPTORES: Salud de las mujeres. Virus del Zika. Microcefalia. Diagnóstico. Epidemias.

INTRODUCTION

Zika virus (ZIKV) infection can lead to a clinical condition of asymptomatic manifestation, alternating with mild and self-limiting symptomatology, leading to possible neurological complications and congenital disease.[1–2] Conceptualized as Congenital Zika Virus Syndrome (CZVS), it was first described in history since the epidemic that occurred in Brazil in 2015.[3–4]

The severe neurological damage in newborns caused CZVS to gain worldwide repercussion. The main complications initially described were microcephaly and brain disorders. In addition, other findings of psychomotor and physical development, Central Nervous System (CNS) problems, such as epilepsy, hearing and visual impairment, osteoarticular sequelae were identified,[3] as well as signs such as cortical-subcortical junction calcifications, cortical development malformations, ventriculomegaly, and abnormalities in corpus callosum formation.[5]

The greatest risk for multiple complications of ZIKV infection is in the embryonic period; however, the CNS remains susceptible throughout pregnancy, depending on the stage of development it is in and various factors associated with the maternal-fetal genotype and peculiar characteristics of the virus pathogenic mechanism.[6] Evidences to the date suggest that most children exposed to prenatal ZIKV infection will develop symptoms by the first or second year of life. A study conducted with 13 children with CZVS without microcephaly at birth showed that all had consistent brain abnormalities coinciding with the syndrome.[7]

The birth of a child is a moment that involves changes and bio-psychosocial adaptations for all family members, especially for the mother. The diagnosis of fetal malformation, regardless of the period, is very striking, bringing the experience of mourning the loss of the idealized baby, permeated by feelings of difficult understanding and expression.[8] When a negative diagnosis is made, the feeling of helplessness, as well as anguish and fear, are emotions that can amount to great concern for the real child,[9] often causing disorders in the family nucleus and having a major impact on maternal health.

Women infected with ZIKV during pregnancy have their lives transformed, with continual changes in many aspects. The cumulative impact of factors such as limited professional knowledge, uncertainties about the consequences of the syndrome, treatment alternatives, as well as family financial and care challenges may include high levels of stress, anxiety and depression, as well as anger and tiredness, which may interfere directly with emotional well-being, with an implication in hope, optimism, physical health and quality of life.[7]

From the problems presented, having CZVS as a new disease, which requires more knowledge and information about both the Zika virus and its complications, the following questions were asked: “How did pregnant mothers with Zika virus become aware of the diagnosis of Congenital Zika Virus Syndrome in their child?; and “How was the diagnosis communicated?”.

Thus, the objectives of this article were to know how mothers affected by the Zika virus during pregnancy knew about the diagnosis of Congenital Zika Virus Syndrome in their child and to understand how the diagnosis was transmitted.

METHOD

A qualitative study with an interpretative approach, based on the Family Resilience, Stress, Adjustment and Adaptation Model,[10] adopted as the theoretical framework of the research. This model provides us with a framework to assist in understanding family responses and the factors related to the adaptation process and changes in response to a family crisis-generating situation, in this context, CZVS diagnosis.

The research had as its scenario a Specialized Rehabilitation Center (SRC) in a city of the state of Paraíba (Brazil) that is a reference for the health care network in various modalities and provides outpatient specialized care in rehabilitation, performing diagnosis and treatment, among other activities.[11] Currently, this service offers coverage to more than 140 cities in the state, in which approximately 100 children with CZVS are registered, so it was chosen as the research site.

The research participants were mothers of children with CZVS from various municipalities of the state of Paraíba. The choice of the mothers was because, in the family context, they are known as caregivers and, in most cases, they accompany their children to health care. During data collection, 48 mothers of children with CZVS were approached; among them, two expressed disinterest in participating in the research; one of them reported having participated in several tiring research studies; in a single instance, there was a mismatch between the researcher and the participant invited, and five women were excluded for not meeting the inclusion criteria, closing the sample in 40 participants.

The inclusion criteria were the following: women over 18 years old with Zika virus in pregnancy (confirmed by laboratory test) and children diagnosed with Congenital Zika Virus Syndrome. The following were excluded: women whose children had microcephaly associated with other causes, women with some type of cognitive disability to participate in the research, who did not reside in the state of Paraíba and who were not registered and attended at the Specialized Rehabilitation Center, as well as mothers of children accompanied by other family members in care.

The semi-structured interview script was developed by the researcher and, in addition, notes were made in a field diary. Data collection took place from June to November2017, after the researcher approached the mothers in the waiting room of the reference service and explained to them the purpose of the research. The selection was made by convenience, according to the mothers' time availability and willingness to voluntarily contribute to the research. After reading the Free and Informed Consent Form, agreement and signature of the participant, the interview began in a closed office, used for multi-professional health care.

The researcher attended the service as many times as necessary during the data collection period, in order to address as many participants as possible. Questions arose around the diagnosis and the family's perception of it, representing the moment in which the family was informed about the possibility of the diagnosis or confirmation of CZVS, as well as the place and form with which it happened, an examination that enabled to get the information, the professional who informed and form of the conduct, possible reactions and feelings in face of the discovery. The interviews were recorded with the aid of a portable digital recorder and transcribed in full for further analysis. The mean duration of the interviews was 20 minutes and 47 seconds. The longest lasted 1 hour, 9 minutes and 29 seconds and the shortest, 9 minutes and 22 seconds.

Final sampling was made by theoretical saturation, when it was understood that there was no further increase in the information obtained. For data organization and analysis, the MAXQDA© software, version 2018 was used, which consists of a qualitative research data analysis program and mixed research methods that allow the researcher a more comprehensive organization and systematization of data, contributing to the process of category building, text coding, analysis and presentation of the results.[12]

The thematic content analysis technique was chosen, which unfolds in three stages: 1) pre-analysis: where preparatory interventions for the analysis are developed, such as choosing the documents to consider or defining the *corpus*; 2) material exploration or coding: process in which the raw data will be transformed and aggregated into units, allowing for an accurate description of the characteristics relevant to the content; and 3) treatment, inference and interpretation of the results, where inferences are proposed and interpretations provided for in the theoretical representation are made, recognizing the information provided by the analysis.[13]

Thus, from the data obtained, a code categorization was constructed for the data analysis, with their respective definitions discussed and reviewed by the researchers, seeking to conform to the theoretical precepts of the referential, allowing the validation. From the codes, two thematic categories were unveiled: the discovery of Congenital Zika Virus Syndrome: period of diagnosis and maternal expectations, and How to communicate the diagnosis: implications for the discovery of Congenital Zika Virus Syndrome.

It is also emphasized that confidentiality and anonymity were guaranteed by adopting the following form of identification: for mothers, the initial M was used, followed by the ordinal numeral that represents the order in which the interviews were conducted (M1, M2, ... And so on). The names of the professionals and health facilities that appeared were replaced by X and XX, respectively.

RESULTS

Until the Zika virus epidemics in Brazil, little was known about the natural history of the disease, since its occurrence was sporadic and limited to outbreaks. Amid so many doubts and uncertainties, the first news appeared in the media and stirred the feelings of pregnant women: *I saw it on television like that, only it didn't show the babies, just the coexistence, these things, what it was... but from the study itself, as now that I have, I didn't know* (M3); *when I was 7 months pregnant I went to have the ultrasound, and I noticed that the baby had a dilated head vein, a brain vein, a brain, a dilation, a change in the head, so I asked the man who was doing the ultrasound and he said: when the baby is born, you follow up with the pediatrician", I was already like that...: what the hell is that? Then, when I noticed, I think that in the same week it started to be aired on television that the babies of mothers who had Zika were being born with microcephaly* (M8).

Although prenatal examinations, such as obstetric ultrasound, are offered by the public health network when recommended, pregnant women also faced uncertainties, misconceptions and lack of sensitivity of health professionals regarding the results, as exemplified in some reports of mothers: *then I asked what the sex of the baby was, because of one I already knew, then she said: 'I'm not even seeing the head, who will say the sex!', then was already understanding... Then I got suspicious, I cried, I despaired...* (M2); *when I went to prenatal care, I showed the doctor on ultrasound, and she said it may be hydrocephalus, but it may be from the training, which in a while may rebuild and the vein back in place, so I was already scared, huh. When I hit ultrasound with 8 months, which aired on television, right? When I knocked, then she said* [...] *She asked if I had any pregnancy infections, so I said: 'His head is small, right?' She said it was, and then I went crazy* [...] *It was then that I asked: 'Is he going to die?' And she said she couldn't say anything about my baby and sent me to find Dr. X. She gave me the money back, I left crying...* (M8); *when I hit 8 months to see if he was OK, then it was found that his head was small for his body size, 28 cm* [...] *at ultrasound the doctor asked if in the family there was someone with a head smaller than the body, then we said: No. My family is all short, but the head is normal. Then he said that his head is very small for his body, his head is only 28. Then I left, but I never imagined it was microcephaly* (M18); *i kept asking anxiously, then they* (referring to the health professionals)*: "No, Mom, we don't even know what it's like yet." And all the questions I made, I kept asking what it would be like, they just said that there would be a follow up, which is normal* (M25).

In many cases, the diagnosis was not clear, as the mothers demonstrated in their speeches: *When the baby was born the other day when I was leaving, the pediatrician said she wanted to talk to me. Then she said that the baby was born with a small head circumference and asked if anyone in my family had a small head, so I said no and then they didn't know it was microcephaly* [...] *Then, since the case was not airing on television, then, when the case started happening, she asked for a tomography and a transfontanel, then confirmed,* (M17); *the doctor didn't tell me it was microcephaly, he just asked if I had anything during my pregnancy, nothing more. He didn't come to me to say she was born with microcephaly, no...* (M23); *when he was born... I only knew that the baby was going* *to be born with a problem, not a special one, but I thought it was a simple problem, the doctor said: 'Look, mom, do you see? Your baby is special.' But he didn't say that either ...* (M25).

Congenital Zika Virus Syndrome discovery: period of diagnosis and maternal expectations

Of the 40 mothers who participated in the research, only 14 were diagnosed prenatally during obstetric ultrasound: *by the time I did the doctor already spoke, said that the head was very small for the time, and said that she had microcephaly* [...] *It was awful. Even before, with three months, I had a beginning of abortion, then the doctor hit the ultrasound and the doctor said she was going to be born with a syndrome. Then it was no longer quiet, and then, later, with this ultrasound, she said it was microcephaly* (M4); *when I was with eight months, I was losing a lot of fluid, feeling a lot of pain, then I went to the maternity hospital to hit an ultrasound, they hit, they hit one in the belly and I couldn't see it, then they hit a vaginal, so they saw that her head was going to be tiny, so they said she was going to be born with a small head, microcephaly* (M10).

The knowledge of prenatal diagnosis was considered negative for M14 and M29, as they experienced the stages of grief before the daughters were born: *on the last ultrasound I hit, it said that the head circumference was below the gestational standard* [...] *I was terrified, because like that, I know all mothers suffered, but you are expecting a perfect child, she was no longer wanted...* (M14); *after I found this out, I almost became depressed, like it were a panic syndrome, I didn't leave home, I didn't feel like anything, I had anxiety crisis, I couldn't sleep, and then... I could not caress my belly, not that I did not like her, is that my anxiety seemed that I would never complete the nine months for her to be born to really see what it was, how I was going to cope, what I could do to take care* (M29).

In relation to the other mothers, eight knew the diagnosis at birth, four at discharge while still in hospital, and nine mothers learned in the postpartum period after complementary exams.

Mothers who discovered CZVS after birth reported being surprised by the news, as they had uneventful pregnancies and prenatal exams were normal: *I didn't have the baby at the hospital anyway, I had the baby at home. Then my mother who held him, then I called the SAMU and cut the umbilical cord, but I had to go to Hospital XX because the placenta was inside, so that's when I found out that the baby had microcephaly, because if the placenta had not stuck, I didn't know until today that the baby had* (M3); *i had the symptoms* (of ZIKV) *with ten weeks of pregnancy. Fever, headache, vomiting, and at the time I did the ultrasound, it only showed that the baby had a fetal tachycardia...* [...] *I didn't find out, I spent the whole pregnancy unknowingly* (M6); *I did four ultrasounds, but they didn't show anything. It was all normal* (M17); *I did yes, I did it with four months, I did it with five months the morphological, but it gave everything normal. I have everything there at home* (M19).

Another five mothers only came to know about CZVS late, after noticing their children's developmental delay: *I stayed in the childcare, but I'm that kind of a picky mom, I went to childcare every month, and I asked the nurse why I was always on the bottom line, and she said she had to keep up with the size of the head that the baby was born with. Only they didn't realize they were substandard. I, as a laywoman on the subject, I am no longer so these days, no, I know everything. Then she said nothing. At three months, I told her that his brother would not hold his head as he should, so she would put him over and he would not raise his head* (M6); *they were already seven months old [...] I found out why they cried so much from colic, I saw them being late developed, but people said it was because they were twins. Then, as they were premature, 35 weeks, then they cried a lot with colic, then I waited the first three months, then it passed. At four months I took her to the pediatrician, and then she thought they had the fontanel closed, and then referred her to the neurologist. By the time the CT scan result came in, they were already seven months old, when he came to say* (M31); *I found out why, when he turned out eight months old, he wasn't developing, so I* *thought it was weird. I took him to the doctor and he did not walk, did not crawl... Then he went to the pediatrician, then the pediatrician asked to go to the neurologist, then I got it from the people I work with, then passed him a resonance and it accused that he had microcephaly* [...] *We took him to the health center to measure the head, right. But it wasn't growing. It stopped* (M40).

During the interviews, three mothers commented that they would rather have discovered the diagnosis during pregnancy: *absolutely. Because, today, there are mothers who had and since the first month they follow, and the boys already walk, the boys already do everything. So, I think so, if I hadn't been late, as I was always charging, I was looking for where I would run, I knew they needed* (M5)*; today he would be another child. Because if at the time he was born the pediatrician had said: 'Look, Mom, I'm not saying your child has anything, but your baby was born with a subnormal head circumference, it has to be over 32 cm'. She would have asked for a transfontanel, she would have done some blood tests, something to see if he...* [...] *They should have made the first calls and would have in the first month of life and not have been six months indoors thinking that my son was normal, that he didn't need assistance, that he needed nothing* (M6); *so, I would like to know in pregnancy, because I was going to have a preparation, both me and my family... Preparing the family, because it was a shock, if we had a preparation before it would be much easier to deal with, because, because it is microcephaly, it would be risky for her to be born in a hospital that does not have an ICU, has no mobile ICU, anything* (M23).

Meanwhile, for M1, the feeling of relief of not being aware of the diagnosis in pregnancy was reported: *I don't know, I think so, I think my world would fall, because I would know I was carrying her, and there would come a thousand thoughts in my head, how she would be, how she would be born...* [...] *Yeah, it was better to know later than load her knowing she was going to have* (M1).

How to communicate the diagnosis: implications for the discovery of Congenital Zika Virus Syndrome

Regardless of the period of discovery, the way the child's diagnostic information was communicated was related to the maternal impact experienced. Of the 23 mothers who positioned themselves, 15 thought they were adequate, while eight reported that the experience was negative.

Although most of the mothers considered that the communication was adequate, they reported that it happened in a normal tone, in order to comply with the professional protocol of transmitting the diagnosis, being the positive form described in detail only by one mother: *it was a doctor,* [...] *Then she said: 'I'll tell you, sit down, but don't be afraid.' Then she explained: 'Your daughter has microcephaly, she will have a problem, but you fight for her.*' (M26); regarding the negative experiences, the reports were stronger: *In truth, I met a real asshole, as I usually say. I knew in the maternity, I was normal, I always went with a companion, and that day I decided to want to go alone, then there was I and other moms sitting there, then she called me, I lay in the bed, and she said: 'Get up, your daughter has microcephaly, percentage of life is as low as possible'* (M24); *she was pretty ignorant, she just said: "Your daughter has micro." And said the malformation she had, which way it was, I don't know what, and that's it. In the same day I found out, I came to another nurse and asked what it was, if she knew what it was, and then she said she didn't know. Then the other day I asked a nurse and she said: 'Mother, don't worry, sometimes he doesn't even get alive from the delivery room'* (M32); *I asked the doctor and she said: "Look, I can't tell you if he will survive today or tomorrow, or if he will die now, I can't tell you." That's when I cried* (M34).

They believed that another approach by the health professional would have better repercussions, as can be seen in the following speeches: *I think it would have been better otherwise, because he arrived like this, I was lying down, I was breastfeeding him, and he came like that, and he took his blood for tests. When he took his blood, he saw it in his book and said: 'Mum, you already know?' – 'No!' –*

'Your son has microcephalus!' She didn't explain anything and left (referring to the professional who gave the diagnosis, but could not certify the profession) (M3). *I think if she had the least understanding, which is such a hard word, I think what I went through would have... She was stupid because, besides you knowing that your daughter is special, she still comes with those words* (M14); *no, so, he had to say he had a problem, I guess so that, if he said it were microcephaly, I would get it all the same, but I didn't know what microcephaly was. I got nervous when the doctor arrived said this and that and said he was a special child, because, so, I thought he was going to die* (M34); *the doctor noticed, then the nurse went to the room, I was lying down, she just arrived and said: 'Your child is suspected to have microcephaly,' that's all. I don't think she was supposed to come and say that. It was a blow* (M39).

An impactful situation, which generated a breach of expectation regarding the idealized son, and shock, was that of M1, who discovered the daughter's diagnosis on her own, reading a document delivered to the child's record: *the doctor said, when she was born he immediately called the pediatrician to evaluate, because if she had an opening in her head, she had to have urgent surgery. Then I said: 'What is it she has?' Nobody brought her to me to see, everybody ran and got her by the side and nobody came to show her to me, I started to get nervous* [...] *Then I stayed there in the beds getting nervous* [...] *Then the doctor lingering there, and the doctor wouldn't come show the girl, and this was me getting nervous. Then, when I went to my room, about 8 hours, 9 hours, then she arrived. Then, when I saw her, they sent her record paper with the name "microcephaly*" (M1).

For M23, the diagnosis was perceived by her herself, when her husband commented that he found his daughter's appearance different, and she related the "small head" with microcephaly: *no one has come to say. When we left there, we went to Campina, who arrived at the hospital and did all the exams, then yes, a social worker arrived and told her exactly what she had. Then yes, but from the hospital no one came to tell me anything* (M23).

DISCUSSION

The results indicated that the news about CZVS was unexpected, regardless of whether it was given before or after birth. Thus, it was possible to identify that many elements are involved in the context of the communication of its diagnosis, from the moment the family receives the news about the possibility or confirmation of the syndrome, as well as the place and form with which it happened, tests that allowed the discovery, reporting professional and manner of conduct.

From the compromised health of the baby, which has resulted in brain malformations such as microcephaly,[14] research studies are still being conducted to reach not only the ways in which the virus is transmitted but also its consequences on birth defects;[7] thus, further knowledge about ZIKV and the implications of infection is needed.[15]

Because it is sometimes asymptomatic, it is often the case that ZIKV infection went unnoticed and many women were unaware that they had it, suggesting that knowledge of exposure during pregnancy can be attributed to causality, with uncertainty as to whether symptoms would be part of the disease. normal course of pregnancy or would be associated with the disease.[7] Constant media discourse, curiosity in social support, and fear of having a child with CZVS have led women to experience different feelings about the epidemic.[16] Thus, the *Internet* and the social networks have become allies of most families to try to find out what they can about the consequences of the syndrome.[7]

The doubts and uncertainties that pregnant women presented during the critical period of the epidemic were also verified by health professionals who, because they were not able to cope with the situation, did not know how to deal with the results of the tests, resulting in so many misconceptions as the ones perceived by the mothers in this research. In a study on the likely impact of CZVS on the families, it was found that both families and professionals will continue to face challenges in achieving accurate and up-to-date knowledge in this situation.[7] The anxiety of receiving the often uncertain news until microcephaly was confirmed was also perceived, and mothers similarly reported that health professionals were unprepared to pass on the diagnosis, using “a hopeless and fatalistic tone.”[17:20]

Microcephaly appears because the brain stops growing. When this happens in the first trimester, it may take a while to get noticed on exams. Ultrasonography (USG) is the diagnostic method of choice, which allows the identification of morphological changes and fetal lesions, often used for fetal screening in risk situations. And, when performed by qualified professionals and following a protocol established by the Brazilian Society of Ultrasonography, it brings evidence of high microcephaly accuracy,[18] Primary Care professionals should be aware of their indications, define the appropriate moment to perform it and be able to interpret the results.[19]

In pregnant women, identification during prenatal care may positively contribute to the success of epidemiological suspicions;[19] however, in the second trimester morphological USG at around 20 weeks, the head circumference may be within normal range, making early diagnosis difficult.[18] Thus, the suspicion and diagnosis of microcephaly are precisely made from the second trimester of pregnancy, with the measurement of head circumference, abdominal circumference and fetal limbs.[18–20]

Although it is a method to certify the health of the concept, in a study conducted with pregnant women in Fortaleza (Brazil), it was revealed that the USG pointed only a momentary tranquility, since the anxiety generated leads to the feeling of short protection, due to ZIKV infection occurs at any stage of the gestational period.[16]

Commonly, microcephaly can be confirmed shortly after delivery by measuring skull size or during routine growth and developmental examinations of infants, which measure height, weight and head circumference. In the screening, newborns with suspected microcephaly, an improvement by the geneticist proposes changes to the protocol adopted by the Ministry of Health, in which, after measuring the head circumference and if indicated, a USG of the baby’s central nervous system is performed. If the result shows severe neurological impairment, the child may be referred directly to a neurologist without the need for CT scan.[21]

Late diagnosis requires imaging, “including transfontanel ultrasonography, brain computed tomography, and/or MRI.”[22:2] An interdisciplinary approach and referral to other specialties may be required for follow-up planning.[22]

Because they are a common stressor in the family unit, the disease and its consequences are related to its magnitude. The way in which the diagnosis will be dealt with, as well as other changes throughout all phases, may result in good or poor adaptation.[10]

There are positive and negative points when receiving the news of the diagnosis in pregnancy, and can be seen positively, as it offers the opportunity for the family to prepare for the arrival of the child, with better acceptance of the syndrome. However, discovery during pregnancy can lead the family to live with feelings of anguish, anxiety and worry.

In a study conducted with family caregivers of children undergoing renal conservative treatment in a pediatric nephrology service in southern Brazil, it was also shown that when the suspected malformation occurs during pregnancy, the mother begins to imagine various diseases, arousing unexpected feelings from confirmation of the diagnosis.[23] In a group of pregnant women, a sense of insecurity was also aroused by so many uncertain news,[16] matching the results found in this search.

In general, these negative feelings that appear at birth can interfere with the mother’s relationship with her child. From the fragments of the discussed speeches, it was possible to understand that these mothers understood that the later the diagnosis is known, the greater the implications for the child’s evolution and the family adaptation process. Thus, the earlier the diagnosis, the better the conditions for the mother and family to face conflicts and restructure to meet the encountered challenges.

How communication of the diagnosis of a congenital malformation or chronic disease occurs is very important for the family members. During this time, dialog must make explanations understandable, while also providing solace for feelings of guilt, uncertainty, grief, and fear,[24] This did not happen in several statements of the interviewed mothers.

From this analysis, the presence of maternal dissatisfaction regarding the way the diagnosis was confirmed was identified. Until the time of the interview, some mothers feel uncomfortable and believe that the negative way in which the diagnosis was informed still affects the initial reaction to it.

A study of mothers of children with microcephaly in three northeastern states also revealed that health professionals are not always prepared for diagnostic information, pointing out as a weakness.[25] Most pregnant women in Fortaleza (Brazil) also reported dissatisfaction with the guidance received.[16]

Regarding the timing of the diagnosis of microcephaly in children in Teresina (Brazil) and the way the news was communicated, many mothers also considered that it was dehumanized, with inappropriate words and without the concern to explain about CZVS and its prognosis, with limitations. and potentialities related to the syndrome itself, confirming that the professional approach, with little involvement and support needed, besides the lack of information, was experienced at various times.[26]

Living with the pain of a diagnosis of congenital malformation, by itself, is already very heavy receiving quality care. From the point of view of words spoken by health professionals abruptly, without care, without affection, and the way mothers were cared for, it has a very important subjective impact on their integral health. Some professionals even trivialized the lives of babies with microcephaly, violating the desire of mothers to have them, to be able to care and love. There is no legitimacy on the part of some health teams regarding the wishes and rights of mothers and their children. Fighting for their babies is what these women have been doing.

In a study with pregnant women in a Fetal Medicine Sector of a public maternity hospital in Rio de Janeiro (Brazil), it was observed that the diagnosis of congenital malformation can have consequences not only for women, but for the couple, from pregnancy to postpartum because it is a risk factor for maternal mental health.[27] This draws attention to the need for new strategies and interventions that better address and refer women to Mental Health services.[28] Because it is a chronic disease, possibly without cure, listening to doubts, complaints and feelings should be emphasized by the mental health professional, who expands his gaze beyond maternal concern, redoubling the provided attention and care.[29]

On the other hand, mothers from Feira de Santana (Brazil), who had children with microcephaly, came across humanized professionals, who presented this qualified listening and understanding of the psychic process experienced and, even in the face of inaccuracies, sought to convey hope and comfort.[30]

The way health professionals transmitted the suspicion or confirmation on the diagnosis became remarkable in the memory of the interviewed mothers, who were able to describe the moment with rich details in their speeches. When the news does not happen properly, the suffering of mothers and family members increases, making the child's acceptance difficult.[30] The welcoming way, clarity of speech, with understandable and practical information, can minimize the impact caused by the diagnosis, with restoring confidence in the follow-up of the disease.[27]

Thus, there should be a planning about how the diagnosis will be provided, aiming to support and clarify any doubts that may arise about the disease. Acceptance and adaptation can be defined based on the sensitivity of the health professional who addresses the diagnosis, as well as all the multi-professional support at all stages, making it essential for empowerment and family balance.[30]

In this context, the multidisciplinary team, with emphasis on nursing, can play a more active role in the availability of clear information and in the recognition of the social support network accessible to the mother and her family members to improve the quality of life and the understanding of these mothers about CZVS, providing increased trust between them and professionals, the strengthening of the bond between mother and child, the approach of the couple and the encouragement for a positive confrontation.

The limitations of the research are centered on the mothers of children with CZVS. Due to the limited space for the elaboration of the article, it was not possible to cover all discursive fragments in the results, however, all participants were included in the analysis and contributed to situate the discussions. Other studies that assess maternal uncertainties are also highlighted, with accurate information, softening the longings that exist based on information and communication about the diagnosis, aiming at maternal strengthening and better family adaptation.

CONCLUSION

Knowledge on the diagnosis and the way it is communicated, as well as the professional conduct at the time of information, played important roles in re-signifying the meaning of congenital malformation. The interaction established by the health professional and their posture are directly related to the satisfaction about the information received.

Regarding the transmitted diagnosis, it was observed that, in most cases, no explanations were offered about the clinical condition of the babies, as well as the prognosis of the syndrome. When the expectation-related wound of the “idealized child” is added to the institutional, obstetric violence, and pediatric and health neglect these women have suffered, their mental health further worsens, when they show the existing processes, such as anxiety, anguish and depression, it is explicit that both mother and family will need special attention and care by health professionals, from prenatal to postpartum.

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NOTES

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Analysis and interpretation of data: Hamad GBNZ, Souza KV.
Discussion of the results: Hamad GBNZ.
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APPROVAL OF ETHICS COMMITTEE IN RESEARCH

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CONFLICT OF INTEREST

There is no conflict of interest.

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