

ORIGINAL ARTICLE

BREASTFEEDING OF CHILDREN WITH MICROCEPHALY IN THE CONTEXT OF THE ZIKA VIRUS

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ABSTRACT

Objective: To understand the perceptions of breastfeeding of mothers of children with microcephaly. Method: Descriptive, qualitative study with 12 women conducted at the outpatient clinic of *Hospital Regional Materno Infantil de Imperatriz*, Maranhão, Brazil, between March and May 2019. The participants were mothers affected by the Zika syndrome in the 2015-2016 outbreak who conceived children with microcephaly. The statements were submitted to content analysis.

Results: The following categories emerged from the women's statements: maternal feelings towards microcephaly; mothers' knowledge about microcephaly; microcephaly and breastfeeding;

challenges in caring for a child with microcephaly; future care perspectives.

Final considerations: Breastfeeding in the context of Zika contributes to improving the quality of life of children with microcephaly. This study contributes to the promotion of breastfeeding children with microcephaly, aiming to promote and support this practice.

DESCRIPTORS: Perception; Breastfeeding; Microcephaly; Zika Virus; Nursing.

LA LACTANCIA MATERNA DE NIÑOS CON MICROCEFALIA EN EL CONTEXTO DE VIRUS DE ZIKA

RESUMEN:

Objetivo: comprender la percepción de madres de niños con microcefalia sobre la lactancia materna. Método: estudio descriptivo, cualitativo, realizado en un ambulatorio de seguimiento del Hospital Regional Materno Infantil de Imperatriz, Maranhão, Brasil, entre marzo y mayo de 2019, con 12 mujeres. Se incluyeron las madres que tuvieron el síndrome de Zika en el brote ocurrido entre 2015 y 2016 y concibieron niños con microcefalia, y los testimonios fueron sometidos a un análisis de contenido. Resultados: con los discursos, surgieron las categorías: sentimientos maternos frente a la microcefalia; conocimiento de la microcefalia por parte de las madres; microcefalia y la lactancia materna; desafíos en el cuidado de un hijo con microcefalia; perspectivas futuras de cuidados. Consideraciones finales: e lacto de amamantar en el contexto del virus de Zika contribuye a la calidad de vida de los niños con microcefalia. Este estudio contribuye a la promoción de la lactancia materna a los niños con microcefalia visando fomentar y apoyar esta práctica.

DESCRIPTORES: Percepción; Lactancia Materna; Microcefalia; Virus Zika; Enfermería.

INTRODUCTION

According to the Ministry of Health (MS)⁽¹⁾, microcephaly is a congenital malformation that affects the brain development of a newborn (NB), whose head circumference (HC) is less than 2 standard deviations from the population average as standardized for age and sex⁽²⁾.

In April 2015, there was an outbreak of cases of congenital malformations, including microcephaly, in Brazil, over a short period of time. In addition to disrupted brain development, neonates had disorders such as arthrogryposis, spinal malformation, microcalcifications in neurological tissue, ventriculomegaly, ocular abnormality and malformations of cortical development ⁽³⁾.

The cases of microcephaly occurred in the state of Pernambuco and surrounded other states in northeastearn Brazil. Since then, the Brazilian and international scientific community have been looking to effectively respond to gaps in knowledge related to the high levels of microcephaly (3). During these investigations, genetic material from the Zika virus was found in samples of the amniotic fluid, corroborating its correlation with microcephaly (4).

The State Department of Health of Pernambuco notified the Department of Health Surveillance of the Brazilian Ministry of Health (MS) about the increase in the number of cases of microcephaly in the state, and on November 11, 2015, the MS declared the outbreak a Public Health Emergency of National Concern (PHENC) based on the alteration of the pattern of occurrence of microcephaly in Brazil⁽⁵⁾. The Zika virus found favorable conditions between 2013 and 2015 in Brazil: a population exposed and a vector, Aedes aegypti, combined with favorable environmental conditions for their proliferation ⁽³⁾.

Between January 2015 and September 2017, 26 countries in the Americas reported 220,693 cases of Zika virus syndrome and 579,700 suspected cases. In Brazil, 4,120 cases were reported in 2015; 8,613 in 2016; 2,658 in 2017; 1,728 in 2018, and 1,163 in 2019. The number of confirmed cases per year of notification was 954 in 2015; 1,927 in 2016; 369 in 2017, and 178 in 2018. In 2019, there were 55 confirmed cases ⁽⁵⁾.

From 2000 to 2014, 2,464 live birth cases with microcephaly were registered in Brazil and in 2015 alone, 1,608 cases were registered. The prevalence rate of microcephaly at birth in Brazil was 54.6 cases per 100,000 live births ⁽⁶⁾.

According to the Epidemiological Bulletin of the Ministry of Health, 498 confirmed cases of growth and development disorders related to the Zika virus infection were reported in Maranhão, corresponding to 3.0% of the population. Of this total, 186 cases were confirmed, 43 were probable cases, seven cases were under investigation, 193 were discarded, seven were inconclusive, and 62 cases were excluded (7).

Given the debate aroused amid the virus outbreak in Brazil in the 2015-2016 period, the question about the risk of breastfeeding transmission of the Zika virus was posed. Although genetic material of the virus was detected in the breast milk of two mothers, recommendation and encouragement of breastfeeding were maintained, as no viral replications associated with the transmission of the Zika virus to neonates were identified. There is no scientific evidence of transmission of the disease through breast milk (8).

Motherhood has substantial meanings that lead mothers to create expectations about their children. Therefore, other issues may influence non-adherence to breastfeeding, triggering early weaning associated to the Zika virus outbreak ⁽⁹⁾. Breastfeeding is beneficial for children with microcephaly, as it favors the development of the Central Nervous System. Therefore, mothers should be advised to breastfeed their children ⁽⁵⁾.

According to the Ministry of Health, the Zika virus syndrome has a major emotional impact on pregnant women. When they receive the diagnosis of fetal malformation, they have negative feelings, ranging from shock and denial to guilt, anger, fear and insecurity⁽⁵⁾.

An open and respectful dialogue with mothers is necessary, in which information about infections, consequences and rights is provided and, above all, relevant psychosocial support is ensured ⁽³⁾. In this context, the present study aims to understand the perception of breastfeeding of mothers of children with microcephaly.

METHOD

Qualitative, descriptive, exploratory study developed at the outpatient clinic of Hospital Regional Materno Infantil de Imperatriz (HRMI), a reference public maternity hospital in southern Maranhão, northeastern Brazil, which provides care to premature infants and children at increased risk of morbidity, and that counts on a multidisciplinary team responsible for the evaluation of these children up to the age of five.

During the study, 38 children were assisted in that service. The subjects were mothers aged 18 or older whose children had microcephaly in the context of Zika virus, in the 2015-2016 outbreak. Mothers of children with microcephaly whose cause was not associated with Zika virus, that is, those mothers who had not been affected by the Zika virus during pregnancy, were excluded.

Intentional sampling and theoretical saturation (10) achieved with the analysis of the 12th interview were used in this study. Two mothers were interviewed at home, as they were no longer attending the clinic for their regular appointments.

Data were collected in individual interviews that lasted in average 20 minutes and were conducted in a private room at the service or at the participants' homes, between March and May 2019. A form based on research previously carried out (11) in the same service containing information on the sociodemographic data of mothers and children's clinics, divided into two parts, was used. The first part includes maternal characteristics (age, education, race/color, marital status, occupation, family income, number of children, place where prenatal care was provided) and neonate characteristics (sex, time of diagnosis of microcephaly, occurrence (or not) of congenital abnormalities, in addition to microcephaly). The second part of the form contained open-ended questions that explored the object of study, which started with the question: what do you know about microcephaly related to breastfeeding?

The interviews were recorded and later transcribed in full. Then, the mothers were referred to the nursing office for the appointments. The two mothers interviewed at home were advised to attend HRMI for the follow-up appointments.

Systematization and data analysis were carried out through thematic content analysis⁽¹²⁾, and five thematic categories emerged: mothers' knowledge about microcephaly; maternal feelings towards microcephaly; microcephaly and breastfeeding; challenges in caring for a child with microcephaly; future care perspectives.

Pseudonyms related to flowers were used to preserve the mothers' identities.

The present study was approved by the Research Ethics Committee of *Universidade Federal do Maranhão*, under protocol no. 1,974,612 of March, 21, 2017.

Twelve women aged 18-38 participated in the study. Seven completed high school (58%); ten declared themselves brown (84%) and eight were married or had a stable relationship (67%); eleven were housewives (92%); nine had a family income lower than one minimum wage (75%); six had between three and four children (50%); ten attended prenatal care at the basic health unit (83%); nine had male children (75%); seven had children diagnosed with microcephaly during pregnancy (58%) and ten had children with microcephaly and other congenital disorders (83%).

Mothers' knowledge about microcephaly

The reports reveal the mothers' poor knowledge about microcephaly:

- [...] I know a little bit, I'm still not very aware of the subject [...]. (Lily)
- [...] Oh, I don't know much. I don't know much about it, because I'm lazy and don't search for this kind of information. I usually search for information about other things [...]. (Orchid)
- [...] I don't know much, but I know the basics [...]. (Magnolia)
- [...] In the beginning it was very difficult, really very difficult, there were many unanswered questions [...]. (Violet)

Maternal feelings towards microcephaly

In the analysis of the mothers' reports when asked about the moment they learned about their children's malformation several feelings emerged:

- [...] We feel disoriented, but at the same time we need to find strength again, because it is an entirely new situation, and then we feel fear and several other mixed feelings [...]. (Tulip)
- [...] I was very sad because I thought I didn't know much about the disease ... so I was very desperate [...]. (Orchid)
- [...] I was a little sad to hear that she had this disease, I have five children, she is the fourth and I never had a child like that, she was born like this, I kind of went crazy [...]. (Sunflower)
- [...] I was shocked, I was anxious and a little depressed, but I'm fine now [...]. (Magnolia)
- [...] Oh, it was very difficult, it was not easy to accept that he had this problem [...]. (Violet)
- [...] I got scared, he was one of the first cases, I was desperate when I left that place [...]. (Azalea)
- [...] I was sad and afraid because we don't have microcephaly, and the doctor who attended me explained to me ... I thought about it and said to my husband: It took me six years to get pregnant and now I give birth to a special son [...]. (Bromeliad)

Microcephaly and breastfeeding

The statements show that most women were able to breastfeed their children, despite the adversities:

[...] I breastfed my baby for over a year, a year and three months. I only stopped it because

- she had an allergic reaction and I was told to stop breastfeeding ...you know sometimes I ended up eating something that was bad for her. [...]. (Orchid)
- [...] I breastfed her until she was 10 months old because afterwards when teething began, she started to bite my breast hurting me [...]. (Camellia)
- [...] Breastfeeding is their main food and up to six months exclusive food, if we are able to offer only milk, it is very good for them. Thank God I was able to exclusively breastfeed my two children for up to six months [...]. (Rose)
- [...] He didn't suck well, he had difficulty sucking. I had a little pain in my breast, but was not hurt. And I managed to breastfeed my child until he was seven months old [...]. (Daisy).
- [...] He didn't want to suck, I couldn't breastfeed him. I only breastfed my son for three months, but he had difficulty sucking, he would suck for a moment and then break away. It was very difficult for me to keep breastfeeding him [...]. (Azalea)
- [...] I know it's important, but he didn't want to suck, I tried it anyway [...]. (Rose)
- [...] He didn't want to suck, I could not breastfeed him. My last two children did not want to suck and now I think it is better this way, because this child is different.. if he grabs my finger, he will bite it ... I guess that if he sucks my breast, It will be very painful.. But the reason why I did not breastfeed him is because he really didn't want to suck. I tried a lot, though unsuccessfully [...]. (Violet)

Challenges in caring for a child with microcephaly

Caring for a child with microcephaly is a daily challenge, as shown below:

- [...] Everything is difficult because he cries a lot, he is stressed, when he starts crying, there is no use doing anything, he only stops when he wants to [...]. (Rose)
- [...] The biggest problem for me is that I live in a small town. I'm in contact with other mothers, and I see that this is the main difficulty, lack of support to give our babies what they need, we have no support and we have to keep fighting to ensure the rights of our babies are protected, but it is useless [...]. (Tulip)
- [...] Food, because sometimes he eats everything, but sometimes he doesn't. I wanted him to eat better, because he doesn't eat well, you know [...]! (Bromeliad)
- [...] Not really, I don't think it's so difficult! Oh, I have a lot of support from my family, I never heard anyone talk about prejudice [...]. (Lily)
- [...] Now I think I am more relaxed. I know how to better deal with him, with this problem. It is very good when we seek help and realize that we are not alone. [...]. (Violet)

Future care perspectives

Reflecting on future perspectives seems to be the spontaneous behavior of every individual. The women expressed their feelings in a choked voice and crying with emotion:

[...] [crying with emotion]. You asked a very difficult question for me. Because the doctors say she is an angel, they say that one day she will leave, you have to give a lot of love, at any moment she may not be with me anymore... in the support groups in which I participate with mothers in the same situation, almost every week a baby dies from pneumonia, choking, fever, I panic even when my daughter just has the flu, and I take good care of her [...]. (Camellia)

[...] Oh! It is very difficult, a lot of people come around asking questions, and I sometimes reply rudely to them, they ask - Oh Will he walk? Oh ... Will he speak? I don't know why nobody knows the answers, right [...]. (Azalea)

[...] I don't even like to think about the future, I learned that it is better this way. At first, when he was born, I kept thinking about how it was going to be, and we almost went crazy. So I don't like to think about the future, I prefer to thank God for the small things that my son has achieved [...]. (Hydrangea)

[...] I think about many things in my son's life: studying, growing up ... I imagine many things. I am very proud to be the mother of a special son. I have no prejudice [...]. (Lily) [...] I think of her growing up, studying and developing and getting big, staying alive [...]! (Sunflower)

[...] I think of him growing up healthy, studying, overcoming life's difficulties and walking [...]. (Magnolia)

DISCUSSION

Microcephaly is a rare congenital abnormality of multiple causes characterized by functional or structural disorders in the central nervous system (CNS). The causes are related to genetic factors and exposure to risk factors such as severe malnutrition, exposure to harmful substances (alcohol, toxic substances and some medications), syphilis, rubella, toxoplasmosis, cytomegalovirus and herpes simplex infections ⁽²⁾. In 2016, a search for studies on the topic, due to the Zika virus outbreak, proved the association of this virus with microcephaly ⁽⁴⁾.

The association of microcephaly with the Zika virus was only confirmed after a relatively long period. Women affected by the infection and the health team itself faced a great enigma. The scenario was uncomfortable for the families involved, and the scientists had no effective answers (3). It was found that many mothers were unaware of the complexity of the dysfunction in their children or had a superficial knowledge about it.

The lack of knowledge on the subject is worrying, since it makes it difficult to offer adequate care to the individuals affected, and therefore understanding the transmission mechanisms of Zika is essential. In this regard, mothers must understand the whole mechanism of their children's illness to know the limitations and needs associated to the care process (13).

Mothers who feel insecure to meet their children's needs may experience depressive feelings, anxiety, denial, shock, guilt and frustration. Women affected by the Zika virus show signs of distress during pregnancy or after childbirth, such as irritability, anger, guilt, shame, or physical symptoms such as tremors, loss of appetite, crying, sadness and anxiety⁽¹⁴⁾.

Pregnant women feel different emotions. Dealing with a difficult diagnosis arouses deep and intense feelings that may have a negative impact on the emotional health of these women ⁽¹⁵⁾. Some of the mothers interviewed reported moments of shock, depressive feelings, denial and frustration.

In a study conducted in Fortaleza-CE, mothers reported feelings similar to those found in the present study ⁽¹⁶⁾. Faced with an epidemic such as that caused by the Zika virus, mothers of children affected by microcephaly exhibit a certain pattern of emotional behavior characterized by anxiety, fear and uncertainty, since experiencing the epidemic experience can result in long-term psychosocial stress ⁽¹⁷⁾.

Motherhood imposes many responsibilities on women and there is a change in

their social role, generating internal conflicts ⁽¹⁸⁾. When abnormalities are detected in the pregnancy, the emotions experienced by women are exacerbated, intensifying their concerns ⁽¹⁹⁾.

Over time, breastfeeding support strategies have been successful, leading many women to adhere to breastfeeding their children exclusively until the age of six months, as recommended by the Ministry of Health. The hypothesis formulated for the association of breastfeeding and microcephaly questioned whether it would be possible to maintain progressive breastfeeding in this context. Despite the difficulties, and the social, psychological and physical changes that occur, the maternal instinct motivates mothers to take care of their children without restrictions ⁽⁶⁾.

Breast milk is essential for children with microcephaly, because in addition to the development of the oral cavity and reduction of the risks of respiratory infections and allergies, it stimulates the orofacial musculature, providing the development of the motor system ⁽⁹⁾. The WHO recommends that women with suspected or confirmed Zika virus breastfeed their children, as there is no evidence of transmission of the virus through breast milk ⁽⁸⁾.

The main difficulties in breastfeeding children with oral and maxillofacial changes reported are poor or inadequate suction, latch-on problems, nasal regurgitation (milk comes out of the nose), choking, low weight gain, low milk supply, breast engorgement and sore nipples ⁽⁹⁾. Such difficulties can be overcome with multidisciplinary support, especially by nurses, with specific guidelines such as the correct position to breastfeed and to manually express some milk before breastfeeding if the areola is engorged ⁽¹¹⁾.

In the present study, a smaller percentage of women were not successful in breastfeeding. It is inferred that these mothers gave up breastfeeding their children, despite being aware of the need to do so. A study carried out in 2015 showed similar results, and some mothers offered artificial milk to their children, contributing to early weaning (20).

Breastfeeding in the context of the Zika virus is possible and contributes to a better quality of life of children with microcephaly. Barriers may arise, such as latch on difficulties and late suction⁽¹¹⁾. However, nursing mothers must be encouraged not to give up. Therefore, health professionals must be attentive to the mother-child binomial, encouraging breastfeeding.

Children diagnosed with microcephaly have delayed motor development and mental retardation ⁽⁹⁾. The routine care of children with such problems is challenging, greater efforts are required to address their basic needs, and face the social stigma of raising a disabled child. The disease can give rise to feelings of guilt, shame and frustration, so that many mothers may not feel able to care for their children ⁽¹⁴⁾.

Children with congenital Zika syndrome have individual and social, health and economic vulnerabilities. They pose a heavy financial burden on their families, due to the high costs of medication, food and transportation (21), as well as specialized assistance for monitoring growth and development (22).

Despite the crisis experienced by some women while taking care of their children after the 2015-2016 epidemic, some respondents managed to adapt themselves to the situation, strengthening family ties ⁽²⁰⁾. Resilience was the positive response of some mothers, as they showed that it is possible to cultivate optimistic perspectives, even though obstacles persist in the development process of their babies ⁽²³⁾.

Children with microcephaly sometimes have health problems, sometimes face life risks and need constant medical assistance, which entails many financial burdens (23). Despite the difficulties to cope with the children's illness (24), some of the women interviewed looked forward to the future with some optimism. Caring for a child diagnosed with Zika virus Congenital Syndrome involves emotional, spiritual, social and family changes, and a care

network must be provided for the child and the mother (25).

A limitation of this study was the fact that some mothers failed to attend their children's multidisciplinary follow-up appointments due to financial difficulties, and other mothers sought more specialized units for the treatment of their children, located in the state capital.

FINAL CONSIDERATIONS

Most women were able to breastfeed their children, despite the adverse factors faced. The mothers' perception of breastfeeding in the context of the Zika virus demonstrated that they know the benefits of breastfeeding for motor-oral, neuropsychomotor and cognitive development, and the children's suffering caused their mothers to show resilience, persisting in breastfeeding their babies.

The mothers had difficulties related to the care demanded by their infants. Active participation of the health care team is suggested to strengthen, support, encourage and educate not only mothers, but also their families.

It is clear that breastfeeding in the context of microcephaly must be supported and prioritized as a perspective of care and health for both children, women and the society, as it provides lifelong benefits to the individuals.

This study contributes to the understanding of the aspects involved in the breastfeeding of children with microcephaly, aiming to promote and support this practice.

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