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Microcephaly in the Maternal-Child Life Cycle

Abstract

Microcephaly is characterized by a complex etiology, in addition to being associated with congenital Zika virus infection, being caused by environmental, genetic factors, metabolism diseases, as well as by the use of drugs and maternal diseases during the gestational period. This study aimed to know the microcephaly in the maternal-child life cycle in the Cariri region and its repercussion on maternal mental health. This is a cross-sectional, descriptive research with a quantitative-qualitative approach, delineated through a descriptive study in the formal statistical analysis for quantitative results. Schutze's narrative was used for qualitative analysis. The study was carried out in inland Ceará in a reference unit for children with microcephaly. Thirteen mothers were interviewed, who have children with microcephaly due to ZIKAV, who had contact with the virus during the fertile period during pregnancy. The profile of the study subject showed that maternal education corresponds to secondary education, 23.1%, with Pardo selfreported colour 92.3%, married marital status 61.5%, with 46.2% as housekeeper occupation, and the mean age of 29.38% (range: 15 to 41 years). The results showed that there is a difference between living conditions of families, knowledge about Zika virus and mothers' feelings about this pathology. Therefore, public policies and health education should be implemented in relation to ZIKAV, in an attempt to reduce cases of microcephaly in the NE of Brazil.

Keywords: Microcephaly; Mental health; Maternal infant; ZIKA V; Pregnancy

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Introduction

Microcephaly presents complex and multifactorial etiology, detected from a screening by measuring the Head Circumference (HC) of the newborn, when there is a HC below two standard deviations from the specific mean for sex and gestational age, being considered severe, when the measurement is below three standard deviations [1-4]. Most often, the reduced head circumference is related to changes in the baby's cognitive system and impaired Central Nervous System (CNS). However, this reduction may not cause an abnormality in brain development in some newborns with microcephaly [5]. Some congenital infectious processes may cause the development of microcephaly. Among them, the most common are: rubella, cytomegalovirus, syphilis, toxoplasmosis and herpes simplex [2,3].

Zika virus (ZIKV), an arbovirus, which presents its form of transmission by mosquitoes, was first isolated in 1947 from a female monkey from the Zika Forest in Uganda, Africa [6]. In Brazil, around one million individuals were infected with this

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viral infection, with the first transmission confirmed in 2015, in April. The Aedes aegypti mosquito is the main vector agent, which caused a state of public health emergency. In Brazil, after the beginning of the epidemic, there was a great increase in the number of confirmed cases of microcephaly, with 1,248 of new suspected cases of microcephaly in neonates [7].

According to the Information System on Live Births (SINASC), there were around 156 new cases of microcephaly registered annually, in the period from 2010 to 2014. However, in 2015, there were 1,248 individuals with the disease [8,9]. In the alarming scenario of the microcephaly epidemic, there was need for a greater contribution of financial investments in Brazil, with emphasis on improving the quality of life and basic sanitation of the population. Access to quality water and basic sanitation are fundamental to increase life expectancy and reduce mortality, especially maternal and child, in addition to vector control and prevention of arboviruses. Furthermore, the effective selective collection of solid waste is essential, promoting a better management of vector control and improvement of the quality of the environment [3].

In Brazil, the presence of intense structural, social and economic inequalities favour the proliferation of insects, lack of adequate structures with basic sanitation, ineffectiveness in the garbage collection process, causes further increase in the proliferation of pathologies. Therefore, it is important to develop assertive and appropriate public policies [10]. Genetic and environmental factors are among the most common causes of microcephaly. Chromosome abnormalities, multifactorial disorders, or variations in Mendelian genetics are present when associated with the genetic factor.

Regarding environmental situations, they can be caused by congenital infectious processes, perinatal hypoxia, drug use, maternal phenylketonuria, and exposure of the uterus to ionizing radiation [11]. However, it is important to know studies on the association of microcephaly with Zika virus in North Eastern Brazil, especially in the Cariri region. Thus, the objective of this study is to know the factors that led to the increase in cases of microcephaly and its repercussion on mental health.

Methods

This is a cross-sectional research of quantitative-qualitative approach, delineated through descriptive study in formal statistical analysis. The study was carried out in inland Ceará in a reference unit for children with microcephaly. The participants of this research were thirteen (13) mothers with children with microcephaly who agreed to participate in the study, who lived in the Cariri Region and participated in the treatment of microcephaly in a reference polyclinic in the treatment of microcephaly, in inland Ceará, in the period from 2015 to 2016, which presented the highest number of cases of microcephaly.

The quantitative results were analyzed through probabilistic approach of the sample from statistical crossings. It is worth mentioning that, initially, the data were organized in tables and graphs. The mean statistical measures, standard deviation and odds ratio were calculated with their respective 95% confidence intervals ($\text{Cl}_{95\%}$). The means were compared, the normality of the data and the equality of variances were verified by the Kolmogorov-Smirnov and Levene tests, respectively. The microcephaly means were analyzed by Student's t-test for independent data and by the F-test. In the latter, when p <0.05, multiple comparisons were made by the Tukey test (if equal variances) and by the Games-Howell test (if unequal variances).

The associations between microcephaly and epidemiological data, as well as sociocultural and environmental factors, were

analyzed by the χ^2 test. Nevertheless, for the correlation analysis between the quantitative variables, Pearson's linear correlation coefficient was adopted and, in cases where the variables are ordinal and in scales, Spearman's rs will be used. The means between two groups will be compared by Student's t-test and those between three or more groups, by ANOVA. Therefore, due to the variances that were unequal by the Levene test, multiple comparisons were made by the Games-Howell test [12].

For all inferential statistical analyses, those with p <0.05 were considered statistically significant. The data were processed in SPSS, version 22.0, and will be triple typed. To obtain the descriptive data of the analysis, the level of education, self-reported color, marital status and occupation were analyzed. The association of the t-test between the variables was used, which considers statistical concepts to reject or not a null hypothesis when the t-test statistic follows a normal distribution of the reference values [12].

To tabulate qualitative data, thematic analysis was used, which recommends the narrative technique according to Schutze F [13]. The technical term originates from the Latin *Narrare*, which means to tell a story. His idea is based on reconstructing social events from the perspective of information, as directly as possible. The information collected through the narrative interview was: gestational age at birth, head circumference at birth, diagnosis, knowledge about the pathology, mothers' feeling when learning about the pathology. For the narrative interview, Schütze F research instrument was used [13-15]. **Table 1** discusses the structure used to form the narrative interview.

The narrative interview is an instrument that was created by Schütze F [13] in the 1980s in Germany, because the processes used at the time for the elaboration of a qualitative research were not sufficient to reliably address the events that were investigated, since the instrument available restricted the participation of the research participants due to its structural rigidity. Weller corroborates Maindock's H [16] understandings, which address the Schutze narrative, showing that, from the unstructured interview, the research participant has the freedom to answer from his/her conceptions and understandings, and not from research questions, trying to understand social phenomena from the individual perspectives of the interviewees.

Schutze F [13], observing the impossibility of a standardized research instrument that fully addressed the particularities of individuals, brought, with the instrument of narrative interview, the possibility of the singular participation of each participant, since their experiences and conceptions of life are related to their reality within the social context being investigated. The present study respected the resolution of the Health Council n. 510 of 2016. Respecting and including the four basic references of bioethics: autonomy, Justice, Beneficence, non-maleficence, among others, guaranteeing the rights and duties of the State, the scientific community and the research subjects. The research was approved by the research ethics committee with a consubstantiated opinion of the REC with number: 2.396.932.

Results

Quantitative results

Thirteen mothers of children with microcephaly due to ZIKAV were interviewed, who had contact with the virus in the fertile period or during pregnancy. The participants' profile reveals: maternal schooling corresponding to secondary education, 23.1%, 92.3% self-reporting Pardo color, 61.5%, were married, 46.2% were housekeepers, and the mean age was 29.38% (range: 15 to 41 years) (**Table 2**).

Knowing the profile of mothers with children with microcephaly is important, because these data allow better understanding the patterns of occurrence and gaps in prevention, thus allowing the development of better strategies for health care. **Table 2** shows a descriptive statistics of the participants, containing information about the following variables: level of maternal education, self-reported color, marital status and occupation. The analysis of **Table 3** indicates that there is an association between negative

feelings of the mothers interviewed regarding Zika (p <0.001) and family living conditions (p <0.001).

Qualitative results

Schutze F [13] advocates the narrative technique, in which the researcher elaborates and put the interview into practice, providing an environment that provides the freedom of response of the interviewees to tell their experiences and singularities lived. The researcher's non-interference in this process is essential. The data constructed from the narrative interview focus on reconstructing, from the view of the participants of the research, the social events that happened, addressing the experiences and exterior and interior particularities of individuals. The impartiality and non-intervention of the researcher during the research are important, allowing obtaining, as a final product, a material crucial to the purposes and objectives under investigation in the Research in Applied linguistics [17].

In the study, it was possible to analyze the narratives of mothers

Table 1 Phases of the Narrative Interview.

Phases	Rules
Preparation	Explore the field,
	Formulate exiting questions (emerge from the research objectives)
Initiation	Formulate the initial topic of the narration,
	Employ visual aids when necessary
Central Narration	Do not interrupt,
	Motivate the continuation of the narration only with non-verbal encouragement
Questioning Phase	Use expressions like "What happened next?"
	Do not give opinions or ask questions about attitudes
	Do not argue about contradictions
	Do not ask questions like "Why?"
	Advance from exiting questions (emerge from the research objectives) to immanent questions (emerge from the interviewee's
	report)
Concluding	Permit questions like "Why?" as gateway for subsequent analysis
Speech	Make notes immediately after the interview

Table 2 Descriptive statistics of the study subjects in relation to profession, colour and schooling, age and marital status.

Variables	N	Percentage (%)									
Maternal Schooling											
Incomplete primary education	2	15.4									
Complete primary education	3	23.1									
Complete secondary education	3	23.1									
Incomplete higher education	2	15.4									
Complete higher education	3	23.1									
Self-Reported Color											
Pardo	12	92.3									
Yellow	1	7.7									
Marital Status											
Unmarried	3	23.1									
Married	8	61.5									
Divorced	2	15.4									
Occupation											
Student	1	7.7									
Farmer	5	38.5									
Housekeeper	6	46.2									
Assistant secretary	1	7.7									
Total	13	100%									

Table 3 Association between knowledge, living conditions and feelings of mothers of children with microcephaly.

		Test Value = 0							
Variables	n (%)	t	df	P-value	Mean Difference	95% Confidence Interval of the Difference			
						Lower	Upper		
		Knowledge About							
Vector	10 (77%)	10.119	12	<0.001	1.231	0.97	1.50		
Proliferation	10 (77%)	10.119	12	<0.001	1.231	0.97	1.50		
Microcephaly	12 (92%)	14.000	12	<0.001	1.077	0.91	1.24		
Relationship between ZIKAV and microcephaly	12 (92%)	14.000	12	<0.001	1.077	0.91	1.24		
Relationship between Sanitation and microcephaly	13 (100%)	7.982	12	<0.001	1.462	1.06	1.86		
		Living Conditions							
Presence of sanitation	7 (54%)	10.156	12	<0.001	1.462	1.15	1.78		
Presence of garbage collection	11 (85%)	11.078	12	<0.001	1.154	.93	1.38		
No health intervention	12 (92%)	10.690	12	<0.001	1.538	1.22	1.85		
Child with microcephaly	13 (100%)	5.790	12	<0.001	2.846	1.78	3.92		
Anxiolytic	1 (9%)	25.000 (8%)	12	<0.001	1.923	1.76	2.09		

^{*}Negative feelings: Sadness, despair, worry, fear, denial and incapacity.

with children with microcephaly. These statements represent feelings that brought moments of uncertainty into their lives. We can analyze some of these narratives according to Schutze. The feelings evidenced in the interviews were despair, shock, sadness, crying, moment of loss, moment of denial and concern, knowledge about the pathology and diagnosis. Mothers with children with microcephaly daily experience difficulties and challenges in the process of caring for their child who has altered growth and development.

One of the feelings most emphasized by mothers during the interviews was the despair they face with this pathology, without resources to treat children. Sadness was also a feeling reported by mothers, frequent in their lives. Some moments of intense crying were observed while describing their feelings in relation to the situation experienced. Moments of loss, denial and concern were quite explicit in their narratives. The concern with the treatment and the future of the child are uncertain in Brazil. The mothers' narratives described the feelings that are present in their lives.

The concern with my son's future and the treatment the government can offer is intense.... (Mother 01).

I have this feeling of loss, as if my son had been taken from me in parts (Mother 02).

Thus far I am shocked with what happened with my son, so much pain and suffering (Mother 04).

The sadness is part of my life. My life is over, people cannot imagine what I feel every day... (Mother 06).

Sometimes, I do not know who I am, nor what I can do for the current situation to get better, so much deception with the public power and the family, few look at me and my son and help me (Mother 07).

The feeling of pain has taken over my life. I do not know what to do with for son to be happy. I think that only the caress and the treatment are not enough (Mother 09).

I cry every day when I see my son, impaired and unprotected (Mother 07).

The pain I feel is too strong, no one can ever imagine what it is to have a son who will never have a normal life like the other children (Mother 02)

My com has so many complications, health changes and frailties. He needs me and a treatment that makes the difference in his life (Mother 05).

I am so afraid that the microcephaly may have affected my sexual and reproductive life (Mother 02).

The UHS has been assisting our children, but it is still not enough... (Mother 07).

Every day I deny this situation, I do not know what my life and my son's expect (Mother 11).

I was shocked when I found out my son would be born with microcephaly (Mother 10).

The despair took over my life and my family's, with no resources, what am I supposed to do... (Mother 13)

Discussion

A survey conducted in the city of Pernambuco showed until 2018 the highest number of cases of babies infected by Congenital Zika Virus Syndrome (CZVS), showing that more than half of the family environment had low income. Of 209 mothers, 77% were below the poverty line and survived in environments with precarious living conditions [18].

The profile of most women infected with the Zika virus was of low educational level, low income, Pardo or black color, young and with difficulty to join the labor market. This demonstrates a profile related to part of the population that is in a state of social vulnerability [19,20], corroborating studies that concluded that most cases of CZVS occurred in families living in disadvantaged and marginalized areas [10,21].

The low family income is alarming, since there will be a greater difficulty in accessing health services, promoting early diagnosis, treatment and rehabilitation, as well as inadequate housing, eating, environmental and hygiene conditions and low adherence to preventive actions of pathologies [22].

In addition to socioeconomic frailties in the family environment, the diagnosis of a congenital malformation is of great impact. Studies showed that parents manifest feelings of suffering, especially due to the disruption of the imagined perfect child's expectation. It also generates processes of denial, pain, anger, mourning for the idealized baby and difficulty in accepting the child with pathology. It is a period when there is the deconstruction of a created expectation, which is experienced in a unique way by each individual [23,24].

Changes in family routine are perceived, promoting focus, time and greater dedication to the child with this pathology, generating an overload of activities and absence of a person who can support care, daily and financial activities [25,26]. However, physical, psychological, social and professional alterations can be developed in their caregivers, who sometimes leave aside their well-being to the detriment of providing care and support to these children [27].

One study showed 19 studies with comparisons between mothers of children with and without disabilities. Of these 19, 16 mentioned greater health problems in mothers of children with disabilities, two addressed higher concerns for the comparative group and one had equal results [28].

It is important that mothers know about the vector and pathology. Misinformation can generate negative impacts on maternal mental health, promoting insecurity in reliable information and fear [29].

Microcephaly develops weaknesses in the child's health, a brain injury that causes changes in motor and cognitive development, depending on the intensity of the injury. There may be changes in the auditory and vision systems, and delay in the neuropsychomotor growth process [30].

The care and support provided to these children should be vigorous, and it is essential that a multidisciplinary team meet and monitor them, because, especially in the first days of life, complications such as cerebral calcifications, arthrogryposis, seizures, difficulty in speech and vision, reduced memory skills may arise [30,31].

Microcephaly has repercussions on the lives of children with this pathology, as well as their families'. It is of paramount importance to follow up mothers and caregivers in the care with the child. Nevertheless, measures to promote the child's health, with emphasis on improving the quality of life of the caregiver and the

one being care for, should be taken by the health authorities. The promotion of health education has an initial and fundamental role to help in the development of autonomy and various ways to improve the quality of life of these people [32].

However, health professionals should promote health education from the guidelines for care and changes that may arise in children, stimulating family participation in the process of caring for children, promoting the understanding of the particular needs of each child and family interaction with the child [33].

These children should receive a holistic look and care, since there are several disorders caused by congenital infection related to Zika. In addition to microcephaly, impacts on auditory, visual and motor development can occur [31,34].

A study showed that children with neuromotor development delays emphasized that health care and service should be multiprofessional, in order to generate an improvement in the quality of life and rehabilitation of these individuals [35].

Microcephaly is considered a public health problem. The multidisciplinary team must be prepared to embrace, guide and stimulate parents during the rehabilitation process of children with microcephaly. Nonetheless, it is important to encourage family members to interact with the child through actions aimed at their development and favor their functionality, autonomy and independence [36-39].

Conclusion

Health professionals, as well as mothers or caregivers, play a relevant role in the care process, promoting an integral and humanized care, for the development of the improvement of the quality of life of these children.

The study showed that feelings of loss, sadness and pain are strongly present in the lives of women suffering the anguish of having a child with microcephaly.

The UHS, with its universal, integral and equitable character, is responsible for carrying out surveillance and health care actions in Brazil. Its role was fundamental for the mobilization of all sectors necessary to cope with the microcephaly epidemic.

The ZIKA virus epidemic has had its cruellest consequences for young, black, poor women and residents in vulnerable areas. These women end up absorbing most of the domestic care, besides often being abandoned by their partners in the face of the situation of the birth of a child with microcephaly.

Therefore, there is a need for greater investment in actions aimed at women's sexual, reproductive and mental health. Public policies should be implemented in Brazil to monitor and care for the emotional and psychological state of women who have children with microcephaly in North-eastern Brazil.

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