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Challenges faced by families living in the context of the congenital zika virus syndrome

Desafíos enfrentados por familias viviendo en el contexto del síndrome congénito asociada a la infección por el virus zika
Desafios enfrentados por famílias no contexto da síndrome congênita associada à infecção pelo vírus zika

ABSTRACT

Objective: to report the main challenges experienced by families of children with congenital Zika virus syndrome (CZS). Method: this is an experience report created from the experience of nurses during research carried out in Mossoró, RN, from 2017 to 2018, with children with CZS and their families. Results: the categories found were: "CZS and difficulties in the family context after the child's birth" and "Gaps between the diagnosis of CZS and integral assistance". Conclusion: the families of children with CZS experience challenges in creating and promoting their health. The need was identified for management agencies and health care professionals in the municipality to commit to the organization of the Health Care Network aimed at these children and their families.

DESCRIPTORS: Zika Virus Infection; Family; Child Health Services.

RESUMEN

Objetivo: relatar los principales desafíos vividos por las familias de niños con Síndrome Congénita Asociada a la Infección por el Virus Zika (SCZ). Método: se trata de un relato de experiencia construido a partir de la experiencia de enfermeras, durante una investigación realizada en Mossoró-RN, de 2017 a 2018, junto a los niños con SCZ y sus familias. Resultados: las categorías encontradas fueron: "El SCZ y las dificultades en el contexto familiar después del nacimiento del niño" y "Lagunas existentes entre el diagnóstico del SCZ y la asistencia integral". Conclusión: las familias de los niños con SCZ experimentan desafíos para la creación y promoción de la salud de las mismas. Se identificó la necesidad de que los órganos de gestión y profesionales de la asistencia en el municipio se comprometan con la organización de la Red de Atención a la Salud dirigida a los niños con SCZ y sus familiares.

DESCRIPTORES: Infección por el Virus Zika; Familia; Servicios de Salud del Niño.

RESUMO

Objetivo: relatar os principais desafios vivenciados pelas famílias de crianças com Síndrome Congênita Associada à Infecção pelo Vírus Zika (SCZ). Método: trata-se de um relato de experiência construído a partir da vivência de enfermeiras, durante pesquisa realizada em Mossoró-RN, de 2017 a 2018, junto às crianças com SCZ e suas famílias. Resultados: as categorias encontradas foram: "A SCZ e as dificuldades no contexto familiar após o nascimento da criança" e "Lacunas existentes entre o diagnóstico da SCZ e a assistência integral". Conclusão: as famílias das crianças com a SCZ experimentam desafios para a criação e promoção da saúde das mesmas. Foi identificada a necessidade de que órgãos gestores e profissionais da assistência no município se comprometam com a organização da Rede de Atenção à Saúde voltada a essas crianças e seus familiares.

DESCRIPTORES: Infecção por Zika vírus; Família; Serviços de Saúde da Criança.

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INTRODUCTION

From 2015, after the outbreak of the Zika virus (ZIKV) and the unusual increase in newborns suspected of microcephaly related to this arbovirus, the Federal Government intensified the strategies for the diagnosis and care of these children by the Unified Health System (SUS) and referring families to obtain benefits and support from the Unified Social Assistance System.¹

In December 2016, Brazil registered 2,205 cases of babies presenting malformation due to maternal ZIKV infection. The Northeast led this picture with 77,2% of registered cases. Pernambuco was the first state to notify the Ministry of Health, the occurrence of babies with a head circumference smaller than expected for their age.²

Microcephaly can result from congenital anomalies or originate after delivery.³ According to Abuelo⁴, genetic microcephaly is expressed by multiple causes, one of which is due to chromosomal changes. In turn, the acquired condition arises from infections, toxins or deprivation states, such as hypothyroidism and maternal malnutrition. Zika virus-related microcephaly is an acquired congenital infection.

Today, there is a consensus that the Zika virus is associated not only with microcephaly, but also with changes in the structure and functions of the body, caused by the inadequate development of the brain, suggesting the Congenital Syndrome associated with infection by the Zika virus (CZS).⁵

According to Brasil⁵, children born

with SCZ have delayed Neuropsychomotor Development (NPMD) right after delivery or during their development.

It is noteworthy that despite the recognition of the impact of CZS, clinical advances and the proposition of assistance actions to be developed with children and their families, the reality experienced by them has been characterized by numerous difficulties, in the family context and in obtaining comprehensive care by SUS.

During the development of academic research in Mossoró-RN to monitor the Growth and Development of children with CZS, socioeconomic and assistance difficulties were verified in the daily lives of families.

This work aims to report the main challenges experienced by families of children with CZS.

METHODS

This is an experience report, built from the experience of undergraduate nursing students at the State University of Rio Grande do Norte (UERN) during the research: Congenital Syndrome associated with Zika virus infection: consequences and factors determinants on the growth and development of children in the first years of life.

The research with no. 56679416.5.0000.5294, on the Certificate of Presentation of Ethical Appreciation (CAAE), was approved by the Ethics Committee of UERN, with opinion no. 1.748.285 of September 27th, 2016.

The study included 12 children with CZS, living in the urban area of Mossoró,

Rio Grande do Norte, and born between the years 2015 and 2016. The exclusion criteria were children whose parents or legal guardians had any mental disorder that interfered with understanding about the data collection instrument and refusing the child's participation in the research; children who moved or whose families intended to move from Mossoró in the 12-month follow-up of CeD.

The participating children were found from the notification forms of the Data Processing Center of the municipality's Health Department or through information from the parents of the first children visited.

Data collection took place between November 2017 and November 2018, at the children's homes, with two to three follow-ups with intervals of 5 months between them, for each child, in order to identify possible limitations and/or potentialities of the CeD.

The pregnant and child health cards, image exams and Neonatal Screening were checked, as well as the "Sociodemographic and Child Growth and Development Questionnaire" was applied to the parents.

The questionnaire contains 162 questions that deal with social and economic aspects, conception, pregnancy, birth, growth, development, socialization and primitive reflexes of the child with CZS.

The collected data were transcribed to the microcomputer, using the Statistical Package for the Social Sciences (SPSS) 20.0 for Windows to organize the database and perform statistical analysis.

The process for analyzing the research data followed specific steps⁶: esta-

blishment of categories; coding, simple and/or crossed tabulation and statistical analysis of the data.

From the students' experience during the application of the aforementioned research questionnaire, two categories emerged that will be presented in the present report: "CZS and difficulties in the family context after the child's birth" and "Gaps between the diagnosis of CZS and the comprehensive assistance".

RESULTS AND DISCUSSIONS

The CZS and difficulties in the family context after the child's birth.

Expectations for the arrival of the perfect and healthy child are abruptly shattered after the birth of a child with malformation. When the diagnosis is informed, the plans change and feelings of fear, anxiety and anguish begin to appear, especially in the mother, who idealized her perfect child.^{7,8}

A struggle then begins between settling for the unexpected situation of a disabled child and preparing to deal with it.⁷

This is one of the difficulties experienced also by the families of children with CZS in Mossoró. The mothers reported, above all, that they lack support, guidance and psychological support to deal with fear and financial difficulties. Despite the existence of the Continuous Installment Benefit (CIB) for children with CZS, family expenses with medications, consultations and travel for professional care, exceed the amount they receive. CIB is equivalent to a minimum wage and was established by the (LOAS - Lei Orgânica da Assistência Social) nº 8.742/931.⁹

In addition to the amount being insufficient due to the expenses that children affected by CZS demand, studies carried out in the context of microcephaly, in northeastern Brazil, also show difficulties for families to access CIB: bureaucratic barriers and validation of the benefit only for families in extreme poverty.⁹

Thus, the birth of a child with a disability and with a greater demand for care,

makes their parents fragile to stress, depression, tiredness, especially the mother, depriving her of social activities and personal care, as well as it can cause impacts on couple's relationships.⁷

In one of the first home visits, a mother reported that the child had not been planned, which motivated her former partner to refuse to carry on with the pregnancy. After 8 months of the baby's birth, when microcephaly was diagnosed, the father broke the emotional bonds, not conforming to the disability, a fact that left the mother emotionally shaken.

A struggle then begins between settling for the unexpected situation of a disabled child and preparing to deal with it

Gaps between the diagnosis of CZS and comprehensive care

In order to provide technical guidance and guidelines to health professionals, for health surveillance and care for pregnant women infected with Zika virus and children with CZS, the Ministry of Health has made protocols available.^{10,5}

Regarding Primary Health Care (PHC), despite one of its attributions, being the monitoring of children's deve-

lopment and the early identification of situations that need to be assisted in a regular and systematic way⁵, the discovery of CZS occurred late, according to some mothers of the research.

Even with the monitoring and carrying out of the necessary tests in the pregnancy period, there was a late identification of microcephaly by health professionals. Four children monitored by the present study were only diagnosed after birth, three of them, between 8 and 12 months of age.

The experience of the late diagnosis of CZS in Mossoró does not differ from the reality of other locations. In a survey carried out in Paraíba with 40 mothers, only 14 knew the diagnosis in prenatal care, during the performance of obstetric ultrasound. Five mothers only came to know about CZS late, after having noticed a delay in the child's development. Eight knew the diagnosis at birth, four at the time of discharge, still in the hospital, and nine took notice in the puerperium, after carrying out complementary tests.¹¹

According to Santos¹², with late diagnosis, the necessary care in the first years of life is compromised. Care assistance needed for these children, such as Early Stimulation, ends up starting too late.

It stands out in relation to the early stimulation activities aimed at children in Mossoró, who initially had to travel to Natal, since the PHC professionals had not received training to carry out these activities. Today, children already receive care for early stimulation in the city of Mossoró, at the Maternal and Child Ambulatory (AMI - Ambulatório Materno Infantil).

In addition, health care for these children must be "carried out by a specialized, multi-professional team, composed of neuropsychiatrists and therapists in the motor and language fields, among others".^{13:3299}

However, despite SUS having as one of its principles, the guarantee of comprehensive care, families of children with

CZS face some obstacles to obtaining it, especially with regard to specialized services, as the municipalities of residence of families do not have such services.⁸

Thus, it was observed during the investigation that there is a lack of a complete team that can provide assistance to children. One of the children diagnosed at 8 months of age, was 1 year and 4 months ago, waiting for the consultation of the Neuropediatrician.

Thus, although currently, Mossoró has institutions to support children and families with SCZ, such as the Center

for Maternal and Child Support (NAMI - Núcleo de Apoio Materno Infantil) of the Faculty of Nursing (UERN) and the AMI linked to the City Hall, still lacks professionals to provide care specifics.

CONCLUSION

The families of children with CZS experience several challenges in raising and promoting the health of these children.

The research to monitor the growth and development of children with CZS revealed social problems experienced

by the family and, therefore, urgent demands for assistance support.

Thus, it is seen that it is essential that the management bodies and professionals responsible for assistance in the municipality, prioritize and mobilize themselves to organize a Child Health Care Network. The need to provide structured services and continuous training of PHC professionals and other levels of care for qualified listening, understanding, meeting the specific needs and psychosocial support of children with CZS and their families is emerging. ■

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