

Children with microcephaly caused by the Zika virus: design and evaluation of sensory changes

Niños con microcefalia causada por el virus Zika: diseño y evaluación de cambios sensoriales

Crianças com microcefalia pelo vírus Zika: delineamento e avaliação das alterações sensoriais

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Abstract

The aim was to identify the main sensory alterations in children with microcephaly caused by the Zika virus and the influence of care overload, using the Burden Interview scale. A cross-sectional study with a quantitative approach. Therefore, data were collected in the outpatient clinic of a tertiary hospital. To characterize the sociodemographic profile of children with Zika virus microcephaly according to the Zarit care burden scale. For the analyses, descriptive statistics and the chi-square test were used. Finally, the care burden score was classified. Head circumference for boys was an average of 29.98 cm and 29.92 cm for girls. Mean age of 3 years and 7 months. Regarding gender, 53% were female. When related to the Zarit scale, females presented 25% from moderate to mild. 72% of the total were children between 3 and 4 years old. In the research findings correlated to the Zarit overload scale, children between 2.5 kg and 4.2 kg presented mild 31.7%. All children had a motor disorder. It is concluded that the most common sensory alterations in children with microcephaly are related to motor, followed by language. Regarding the burden of care, they presented mild.

Descriptors: Children's Health; Zikavirus; Microcephaly; Cephalometry; Neurological Disorders.

Resumen

El objetivo fue identificar las principales alteraciones sensoriales en niños con microcefalia provocadas por el virus Zika y la influencia de la sobrecarga de cuidados, utilizando la escala Burden Interview. Estudio transversal con enfoque cuantitativo. Por lo tanto, los datos fueron recolectados en la consulta externa de un hospital de tercer nivel. Caracterizar el perfil sociodemográfico de los niños con microcefalia por el virus del Zika según la escala de carga de cuidado de Zarit. Para los análisis, se utilizaron estadísticas descriptivas y la prueba de chi-cuadrado. Finalmente, se clasificó la puntuación de carga de cuidado. El perímetro cefálico de los niños fue en promedio de 29,98 cm y de 29,92 cm para las niñas. Edad media de 3 años y 7 meses. En cuanto al género, el 53% eran mujeres. Cuando se relacionó con la escala de Zarit, el sexo femenino presentó un 25% de moderado a leve. El 72% del total eran niños entre 3 y 4 años. En los hallazgos de la investigación correlacionados con la escala de sobrecarga de Zarit, los niños entre 2,5 kg y 4,2 kg presentaron leve 31,7%. Todos los niños tenían un trastorno motor. Se concluye que las alteraciones sensoriales más comunes en niños con microcefalia están relacionadas con la motricidad, seguida del lenguaje. En cuanto a la carga de cuidado, presentaron leve.

Descriptores: Salud de los Niños; Virus Zika; Microcefalia; Cefalometría; Desórdenes Neurológicos.

Resumo

Objetivou-se identificar as principais alterações sensoriais em crianças com microcefalia pelo vírus Zika e a influência da sobrecarga de cuidados, através da escala Burden Interview. Um estudo transversal de abordagem quantitativa. Portanto, os dados foram coletados no ambulatório de um hospital terciário. Para caracterizar o perfil sociodemográfico das crianças com microcefalia pelo vírus Zika conforme a escala de sobrecarga de cuidados de Zarit. Para as análises, utilizaram-se da estatística descritiva e do teste Qui-quadrado. Por fim, foi feita a classificação do escore de sobrecarga de cuidados. Perímetro Cefálico dos meninos foi média de 29,98 cm e 29,92 cm para as meninas. Média de idade de 3 anos e 7 meses. Em relação ao sexo, 53% eram feminino. Ao ser relacionado à escala de Zarit, o sexo feminino apresentou 25% de moderada a leve. 72% do total eram de crianças entre 3 e 4 anos. Nos achados da pesquisa correlacionados à escala de sobrecarga de Zarit, as crianças entre 2,5 Kg e 4,2 Kg apresentaram leve 31,7%. Todas as crianças apresentaram distúrbio motor. Conclui-se que as alterações sensoriais mais comuns nas crianças com microcefalia estão relacionadas ao motor seguido de linguagem. Em relação à sobrecarga de cuidados, apresentaram leve.

Descritores: Saúde Infantil; Zika Vírus; Microcefalia; Cefalometria; Desordens Neurológicas.



Introduction

The first case reports of Zika virus (ZIKV) in humans occurred in Nigeria, in 1954. It is an arbovirus of the flavivirus genus (Flaviviridae family). In 1947, ZIKV was already known in Uganda in the Zika Forest. This virus was isolated from rhesus monkeys. In Brazil, the vector that transmits the Zika virus is *Aedes (Stegomyia) aegypti* (Diptera: Culicidae)¹⁻³.

The numbers of cases of microcephaly related to the Zika virus in Brazil, in 2015, drew the attention of Brazilian authorities. Among them, the Ministry of Health. Consequently, the Brazilian teams partnered with the Pan American Health Organization and the World Health Organization (PAHO/WHO), since the prevalence coefficient of microcephaly in children at birth was 54.6 cases per 100,000 live births. Mainly in Pernambuco, there was an increasing number of cases, which persists until the present day. Currently, there are 449 confirmed cases of ZIKV microcephaly. Of this total, there were 272 cases in 2015, 161 in 2016, 22 in 2017 and 2 in 2018⁴⁻⁷.

Microcephaly is not a pathology in itself, but it is considered a disturbance in brain growth. It is categorized as primary when the origin is genetic, chromosomal or through infections. Anomalies of the Central Nervous System (CNS) are related to the gestational age at which the event occurred, that is, the earlier the condition, the greater the severity of the most frequent neurological alterations: motor, intellectual disability, epilepsy, cerebral palsy, dysphagia, visual and hearing impairment, as well as behavioral changes⁸⁻¹¹.

Taking care of a special child over time can also entail an overload for the caregiver, formed as a result of a disturbance when facing the physical dependence and intellectual disability of the individual, due to the attention and care needs that the other needs. The quality of life is directly proportional to the burden of care, as the greater the burden of care, the more difficult the perception of the quality of life that the caregiver has¹².

Thus, to achieve the objective of the study, it is necessary to identify the main sensory changes in children with microcephaly caused by the Zika virus and the influence of care overload, through the Burden Interview scale.

This research asked the following question: what are the sensory changes suffered by children who contract microcephaly due to the Zika virus, and in what proportion do they act in the child's body?

Methodology

This cross-sectional, exploratory-descriptive study, with a quantitative approach, was conducted at the Oswaldo Cruz University Hospital of the University of Pernambuco (HUOC/UPE), located in the city of Recife, State of Pernambuco, Brazil. It is a reference institution in the care of children with microcephaly caused by the Zika virus. The study population consisted of 60 caregivers of children with microcephaly associated with the Zika virus.

As a selection criterion, caregivers of children diagnosed with microcephaly due to the Zika virus who were treated at the referred health center were included. Caregivers who refused to participate in the study, even

after signing the Free and Informed Consent Form (TCLE), were excluded, as well as caregivers who entered the unit less than six months ago and visually impaired caregivers. The sampling selection method was for convenience, since it presented a small number in the sample.

The variables studied were: sex, age, weight, head circumference, difficulty of the child to swallow, recurrence of choking. In addition to these factors, the presence of such sensory alterations: motor deficit, language deficit, auditory deficit, visual deficit.

The instruments for data collection were a self-applicable sociodemographic questionnaire and the Zarit Care Burden Scale (Burden Interview Scale) to analyze the burden of caregivers of children with microcephaly. This care scale, created by a group of researchers led by Steven Zarit, a professor at the University of Pennsylvania, was translated and validated for Brazil by Scazufa¹³.

Data collection took place in the pre-consultation (waiting room). All caregivers who met the inclusion criteria were invited to participate in the research. They received information about the content of the research, in which all doubts were clarified and they were assured the secrecy of both their identities and the data collected. The data collection period took place between July 2019 and January 2020.

To characterize the profile of children with microcephaly, percentage frequencies were calculated and the respective frequency distributions constructed. In the analyses, descriptive statistics were used with quantitative variables described by median and interquartile range (IQR), as well as categorical variables by proportions and, finally, the Chi-square test to verify whether there is a relationship between caregivers' burden of care and the variables: sex, age, weight, difficulty of the child to swallow, recurrence of choking, with a statistical significance level of $p < 0.05$, through the software (R version 3.4.1 and SPSS for Windows version 12).

Finally, the care burden score was classified. Each item received a score ranging from 0 to 4 on the Likert scale as follows: 0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = always. The sum of the scores was considered as follows: no overload (score less than 21 points), mild overload (21 to 40 points), moderate overload (41 to 60 points) and high overload (61 to 88 points). All conclusions were apprehended considering the significance level of 5%.

It should be noted that all ethical and legal aspects were respected, as recommended by Resolution No. 466/12 of the National Health Council.

The study was approved by the Human Research Ethics Committee (CEP) of the Centro Universitário da Faculdade de Medicina do ABC Paulista based on Opinion No. 3,373,788, under the Certificate of Presentation of Ethical Appreciation (CAAE): 13840419.6.0000.0082.

Data collection took place after approval by the CEP and signature of the TCLE by all participants.

Results

Of the total of 60 children who contracted microcephaly due to the Zika virus, as shown in (Table 1), the



mean age was 3 years and 7 months. Of the total number of children, 72% were between 3 and 4 years old. Regarding sex, females predominated with 53%. The head

circumference of boys had an average of 29.98 cm and 29.92 cm for girls.

Table 1. Outline of children with microcephaly by Zika virus related to the Zarit scale. Recife, PE, Brazil, 2022

Variables		ZARIT SCALE									
		High		Moderate		Mild		Absence		Total	
		n	%	n	%	n	%	n	%	n	%
Gender	Male	0	0,0	7	11,7	13	21,7	8	13,3	28	46,7
	Female	1	1,7	10	16,7	15	25,0	6	10,0	32	53,3
	Total	1	1,7	17	28,4	28	46,7	14	23,3	60	100
Age	0 to 1 year	0	0,0	1	1,7	1	1,7	0	0,0	2	3,3
	1 to 2 years	0	0,0	0	0,0	4	6,7	0	0,0	4	6,7
	2 to 3 years	0	0,0	2	3,3	3	5,0	1	1,7	6	10,0
	2 to 4 years	1	1,7	12	20,0	18	30,0	12	20,0	43	71,7
	> 4 years	0	0,0	2	3,3	2	3,3	1	1,7	5	8,3
	Total	1	1,7	17	28,3	28	46,7	14	23,3	60	100
	Weight	< 2,5 kg	0	0,0	4	6,7	5	8,3	4	6,7	13
2,5Kg - 4,2Kg		1	1,7	13	21,7	19	31,7	8	13,3	41	68,3
> 4,2Kg		0	0,0	0	0,0	3	5,0	1	1,7	4	6,7
Did not inform		0	0,0	0	0,0	1	1,7	1	1,7	2	3,3
Total		1	1,7	17	28,3	28	46,7	14	23,3	60	100

Regarding the assessment of the burden of caring for children (Table 1), sex, weight and age were classified as mild, males 22% and females 5%. The age between 3 and 4 years represented 30% of the sample and in relation to weight, children who were born between 2.5 kg and 4.2 kg showed 32%.

Table 2 identifies the categorical questions presented to caregivers of children with microcephaly caused by the Zika virus and the relationship with the Zarit scale of care. The following questions were investigated using a standardized questionnaire, “what makes it difficult for the child to swallow”, “has choking ever occurred”.

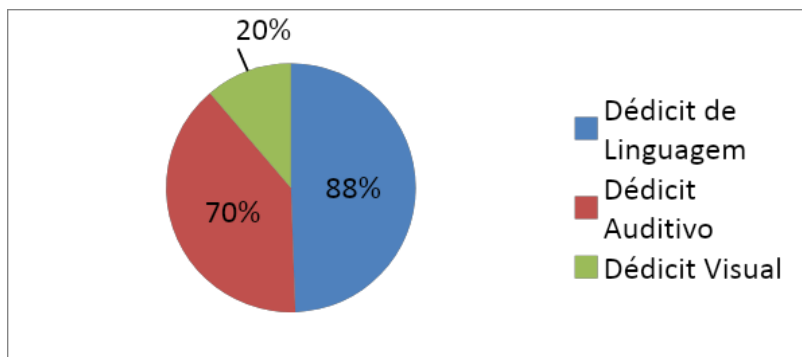
Table 2. Design of categorical variables: “Difficulty of the child to swallow”, “Presented choking”, and the relationship with the Zarit care scale. Recife, PE, Brazil, 2022

Variables		ZARIT SCALE									
		High		Moderado		High		Ausência		High	
		n	%	n	%	n	%	n	%	n	%
Deglutition	No problem	0	0,0	9	15,0	19	31,7	10	16,7	38	63,3
	Dysphagia	1	1,7	6	10,0	8	13,3	4	6,7	19	31,7
	Spit	0	0,0	2	3,3	0	0,0	0	0,0	2	3,3
	Cough	0	0,0	0	0,0	1	1,7	0	0,0	1	1,7
	Total	1	1,7	17	28,3	28	46,7	14	23,3	60	100,0



Choking	Yes	0	0,0	4	6,7	11	18,3	5	8,3	20	33,3
	No	1	1,7	13	21,7	17	28,3	9	15,0	40	66,7
	Total	1	1,7	17	28,3	28	46,7	14	23,3	60	100,0

Figure 1. Deficit of sensory alterations presented by children with microcephaly caused by Zika virus. Recife, PE, Brazil, 2022



The description in Figure 1 details the sensory changes presented by children with microcephaly caused by the Zika virus. It is observed that 100% of the children had a motor deficit.

Discussion

Children with microcephaly caused by the Zika virus are confronted daily with the challenges imposed by their difference in brain development and growth, affecting other organs. These children are being treated by the multidisciplinary team in order to promote the well-being of all those who receive care from the team.

The survey results show that the children were mostly female, with an average age of 3 years and 7 months. These characteristics are described in studies^{14,15} performed in children with Zika virus microcephaly. By determination of the Ministry of Health, the following criteria were defined for identifying newborns at risk: family with low family income (monthly earnings between R\$70.01 and R\$140.00 per person), children who were born prematurely estimated for age (<37 weeks) of gestation, who has approximately low birth weight (<2,500 g), in addition to serious illnesses¹⁶.

The variables in Tables 1 and 2 (gender, age, weight, head circumference, child's difficulty in swallowing, recurrence of choking), in relation to the caregiver's burden of care, were classified as mild. This result was found in other studies^{17,18}, in which the burden of care was classified as mild. The findings describe that the children were mostly female.

Prematurity is multifactorial and, in relation to the mother, one can include demographic space, social behavior, nutritional transition, previous pregnancies, recurrent infections, biological factors. As for newborns, 10% of babies in Brazil are born preterm. One of the methods used in reciprocal benefits in the mother-child binomial is the kangaroo method¹⁹.

Some studies demonstrate the importance of prenatal care recommended by the Ministry of Health of at least six appointments. In addition, childcare care is necessary, as well as paying attention to the risk criteria for

a NB, and not failing to observe the associated factors, following the standardized criteria for the number of consultations in the first week of life, as well as the monthly consultations up to two years of age. It is worth mentioning that, for children with microcephaly, it is necessary to carry out hearing and ocular screening, in addition to doing fundoscopy of the eyes. When a newborn has conditions and alterations in growth and development, increasing neuropsychomotor morbidities, in addition to attention deficit disorders, hyperactivity, abnormalities in vision, hearing, among others²⁰.

The Ministry of Health, in its health care protocol, in response to the occurrence of microcephaly, emphasizes the importance of carrying out hearing and eye screening, in addition to fundoscopy in these cases. It is observed that exposure to the virus is aggravating the health of the fetus and the baby, being a risk factor for morbidities²¹.

In general, children have some difficulties in feeding themselves, which may be related to swallowing disorders, choking (which is a defense of the body in expelling objects), diets, and may result from the need for hospitalization due to bronchoaspiration, with the aim of pneumonia and even death. Such questions point to a need to plan care for caregivers, covering the difficulties presented. It is a manifestation of the body to expel food or object that takes a "wrong way" during swallowing. At the top of the larynx is the epiglottis, a structure composed of cartilaginous tissue, located behind the tongue. It works like a valve that remains open to allow air to reach the lungs and closes when we swallow something, this to block the passage of food into the lungs and forward it to the stomach. Choking is considered an emergency, and in severe cases, it can lead to death by asphyxiation or leave you unconscious for a while. Therefore, acting quickly avoids complications²².

Conclusion

By observing the aspects analyzed, it was concluded that the most common sensory alterations in children with microcephaly are related to motor, followed by language. The children's personal profile questionnaire showed an



average age of 3 years and 7 months. Regarding gender, the majority were female (53%). When correlated with the Zarit scale, females had 25% mild. 72% of the total were children between 3 and 4 years old. In the research findings correlated to the Zarit overload scale, children between 2.5Kg and 4.2Kg presented mild (31.7%). All children had motor disorder.

Based on this knowledge, there is a need for stimulation, so that the environment in which the child lives becomes a determining factor in the variety of stimulation necessary for development. Evidence on the subject indicates that sensory and motor stimulation should be provided by the family and the multidisciplinary team as early as possible. However, there is a need for more studies on the sensory issues of children with microcephaly and their future outcomes.

The absence of primary care programs for

caregivers enhances the factors that generate overload. An investment in support prevention for these patients will influence a better quality of both the caregivers and the children, minimizing the burden of care.

This study had a small sample size as a limitation. It is suggested that further research be carried out with a larger sample, in order to relate children with microcephaly caused by the Zika virus with the overload of care, aiming at a better understanding and clarification of the difficulties presented and other factors that are responsible for the overload of caregivers.

In view of the above, it is understood that children with microcephaly caused by the Zika virus trigger a mild care burden, and it is possible to observe the need to develop and implement support programs and primary health care for caregivers of children with microcephaly in order to reduce the impacts on caregivers.

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