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RESEARCH

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EVOLUTION OF OVERLOAD IN MOTHERS OF CHILDREN WITH CONGENITAL ZIKA VIRUS SYNDROME

*Evolução da sobrecarga de mães de crianças com síndrome congênita do zika vírus**Evolución de la sobrecarga en madres de niños con síndrome congénito por el virus zika***Anna Karolyna da Silva Queiroz de Sá¹** **Gabriela Eiras Ortoni²** **Thereza Cristina Rodrigues Abdalla Veríssimo³** **Monica Izabella Chagas Moreira⁴** **Maysa Ferreira Martins Ribeiro⁵** **Cejane Oliveira Martins Prudente⁶** 

ABSTRACT

Objective: to analyze the progress of the physical, emotional and social overload from mothers of children with Congenital Zika Virus Syndrome (CZVS). **Method:** 22 mothers and their respective sons with CZVS participated. They were inserted in a State Rehabilitation Center. Sociodemographic and clinical evaluations questionnaires were applied, the scale Gross Motor Function Classification System Scale (GMFCS), and Informal Caregiver Burden Assessment Questionnaire (ICBAQ). **Results:** there was an improvement in the mothers' burden of care in relation to the financial aspect ($p < 0.01$) and a worsening in the mechanism of effectiveness and control ($p = 0.04$) and satisfaction with the role and the family ($p < 0.01$). **Conclusion:** the overload of caring from mothers of CZVS children presented improvement and worsening on different aspects during the follow-up period. The family support network should be strengthened and specialized care provided by a multidisciplinary team should be guaranteed.

DESCRIPTORS: Zika virus; Overload; Caregiver.

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RESUMO

Objetivo: analisar a evolução da sobrecarga física, emocional e social de mães de crianças com Síndrome Congênita pelo Zika Vírus (SCZV). **Método:** participaram 22 mães e seus respectivos filhos com SCZV, inseridas em um Centro Estadual de Reabilitação. Foram aplicados questionários de avaliação sociodemográfica e clínica, a Escala Gross Motor Function Classification System (GMFCS) e o Questionário Avaliação de Sobrecarga do Cuidador Informal (QASCI). **Resultados:** houve melhora na sobrecarga do cuidado das mães em relação ao aspecto financeiro ($p < 0,01$) e piora no mecanismo de eficácia e controle ($p = 0,04$) e satisfação com o papel e o familiar ($p < 0,01$). **Conclusão:** a sobrecarga do cuidado de mães de crianças com SCZV apresentou melhoras e pioras em diferentes aspectos durante o período de acompanhamento. Deve-se fortalecer a rede de apoio familiar e garantir cuidado especializado, por uma equipe multiprofissional.

DESCRITORES: Zika vírus; Sobrecarga; Cuidador.

RESUMEN

Objetivos: analizar la evolución de la sobrecarga física, emocional y social de las madres de niños con Síndrome Congénito por el Virus Zika (SCZV). **Método:** participaron 22 madres y sus respectivos hijos con SCZV, insertados em um Centro Estadual de Rehabilitación. Se aplicaron cuestionarios de evaluación demográfica, clínica y de sobrecarga del cuidador. **Resultados:** El estudio mostró que hubo una mejora en la carga de cuidado de las madres en relación al aspecto financiero y un empeoramiento en el mecanismo de efectividad y control, siendo las más afectadas en el segundo cobro, y la satisfacción con el rol y el miembro de la familia. **Conclusión:** la sobrecarga mostró mejoras y empeoramientos en diferentes aspectos. Esto se debe a las diferentes perspectivas de estas madres. La pandemia parece haber influido en el empeoramiento de algunos dominios, pues centralizó aún más los cuidados en la madre.

DESCRIPTORES: Virus zika; Sobrecarga; Cuidador.

INTRODUCTION

The Zika virus (ZIKV) is a flavivirus of the Flaviviridae family discovered in 1947 in Uganda, East Africa.¹ Its main form of transmission is through the bite of mosquitoes of the genus *Aedes* and, mainly, by *Aedes aegypti*.² With an increase in the number of cases of newborns with microcephaly after the occurrence of Zika virus fever in the same region, it was realized that ZIKV is associated with other congenital changes, constituting the Congenital Zika Virus Syndrome (CZVS).³⁻⁴ In Brazil, between 2015 and 2021, 20,444 suspected cases of CZVS were reported, of which 1,834 were confirmed.⁵

The main clinical findings in this syndrome are craniofacial disproportion with a microcephalic appearance, associated with calcifications predominantly at the cortical-subcortical junction, ventriculomegaly, malformations of cortical development and abnormalities in the formation of the corpus callosum.⁶ Associated with this condition are marked early hypertonia, with symptoms of extrapyramidal involvement, macular scarring and focal mottled pigmentation of the retina.⁷ In addition, impairment of gross motor function is also a relevant clinical finding, as most children are unable to perform simple tasks.⁸

The arrival of a baby in the family implies a transformation in their life habits, as well as reorganization of roles within the family structure. However, the birth of a child with a disability is even more impactful, constituting a traumatic and disruptive event that interferes with family balance.⁹ The daily life of mothers of children with CZVS is very tiring, due to the intense and specific demand with medical care, in addition to domestic duties and care for other children, increasing responsibility.¹⁰ In addition, because

they are, in most cases, the only caregivers of the children, they experience intense moments of exhaustion and abdication, with changes in family dynamics, lifestyle and marital relationship.¹¹

The overload of caregivers, mostly mothers, of children with chronic diseases is one of the factors that most generate negative impacts on the lives of those involved. This overload occurs due to the accumulation of tasks and responsibilities that go beyond what is expected in a maternity, making it impossible to perform tasks outside this context, such as leisure activities, compromising the quality of life of these mothers. The literature shows that the increase in overload is related to some factors such as the absence of a partner, unemployment, decreased social interaction, sleep deprivation and low level of education.¹²

Studies that analyzed the burden of care in mothers of children with CZVS, using quantitative instruments, are still scarce.¹³ Considering the relevance of the theme and aiming to bring more visibility to this group, it is necessary that such studies are carried out, so that more effective public policies are created and these mothers and their children are properly assisted. Given the above, the objective of this study was to analyze the evolution of the physical, emotional and social burden of mothers of children with CZVS.

METHODS

This is a longitudinal and observational study. The sample consisted of mothers and their respective children diagnosed with CZVS, inserted in a State Rehabilitation Center in Goiânia-GO, a reference in the state in the treatment and follow-up of children with CZVS, with care exclusively by the Unified Health System (SUS).

Children with confirmed and exclusive diagnosis of CZVS (C-reactive protein - PCR reactive for Zika virus and/or CT image attesting to neurological alteration), who were being treated at the institution and their respective mothers were included; and children with other neurological pathologies associated with CZVS, other caregivers of children other than mothers and mothers under the age of 18 were excluded.

Data collection occurred in two moments, with an interval of eighteen months; before the COVID-19 pandemic (May to July 2019) and during (November 2020). Thirty mothers and their children participated in the initial data collection; of these eight did not continue treatment or it was not possible to contact them in the second collection. Thus, the study ended with 22 mothers.

In March 2020, the pandemic caused by SARS-CoV-2, known as coronavirus, began. During this period, as a measure to prevent the spread of the disease, face-to-face therapies were canceled at the institution, remaining by telecare. The return of face-to-face therapies occurred in September of the same year. However, some children did not return to attend them in person, continuing in the online format.

The instruments applied were the Mothers' Sociodemographic and Clinical Assessment Questionnaire; the Child's Clinical Assessment Questionnaire, the Informal Caregiver Overload Assessment Questionnaire (QASCI) and the Gross Motor Function Classification System (GMFCS) Scale.

The evaluation questionnaires were developed by the researchers. The variables analyzed from the mothers addressed sociodemographic aspects such as city of residence, schooling, marital status, taking turns caring for the child with other people, number of children, leisure activities, health plan, therapy, family income, current work, type of residence, benefit and transportation; and the variables analyzed from the children contained data such as gender, microcephaly classification, GMFCS level, physiotherapy, speech therapy and occupational therapy.

The z-score of the cranial perimeter was calculated using the Intergrowth-21 calculator, which uses international anthropometric parameters for newborns, aiming to identify early children with abnormal values, which may or may not reflect some clinical conditions. The value considered normal for cranial perimeter varies according to gender and gestational age.¹⁴

The QASCI is a questionnaire that assesses the physical, emotional and social burden of the informal caregiver. It consists of 32 items that analyze the implications on personal life (11 items), satisfaction with the role and with the family member (5 items), reactions to demands (5 items), emotional overload (4 items), family support (2 items), financial overload (2 items) and perception of efficacy and control mechanisms (3 items). There are five response categories: no/never, rarely, sometimes, almost always and always. The final score is the result of the total sum of the answers obtained for the 32 items (possible range 32 to 160) referring to each domain, divided by the total number of domains or by means of the average of the items (range one to five), after the inversion of the scores of the items of the three positive dimensions. Higher values correspond to situations with greater weight or greater burden.¹⁵

The GMFCS determines the level of a child or young person's gross motor function abilities and limitations. This classification has 5 levels. The child in level I is able to walk; in level II can walk, but with limitations; in level III has a gait with locomotion aids; in level IV independent locomotion is very limited and may use a motorized wheelchair; and in level V the child does not locomote independently and needs to be transported.¹⁶

The selected mothers went through the consent process and signed the Informed Consent Form. The questionnaires were applied in the form of interviews at two different times. The first data collection took place in person and the second via telephone call. The children's electronic medical records were analyzed to complete the sociodemographic and clinical evaluation questionnaires. Only in the first data collection, the children were evaluated using the GMFCS instrument.

The characterization of the sociodemographic profile of the mothers and the profile of the children was performed using absolute frequency, relative frequency, mean and standard deviation. The Shapiro-Wilk test was applied to verify whether the continuous variables had a normal distribution. If the normality of the data was not verified, non-parametric tests were applied. The assessment of overload was tested before and after the follow-up period using the Wilcoxon test. The data were analyzed using the Statistical Package of Social Sciences (SPSS, 26.0). The significance level adopted was 5% ($p < 0.05$).

The study was approved by the Ethics Committee for Research with Human Beings of the Pontifical Catholic University of Goiás (PUC Goiás), under opinion No. 3.237.062, according to Resolution No. 466, of December 12, 2012.

RESULTS

The study ended with 22 mothers and their respective children diagnosed with CZVS.

Table 1 presents the characterization of the sociodemographic profile of these mothers, in relation to the first collection. The mothers had a mean age of 31.91 ± 6.37 years. All mothers were the main caregiver and none had a chronic disease.

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In the second data collection, there was a small increase in the percentage of mothers who lived in Goiânia and the Metropolitan Region (59.1%), who took turns caring for someone else (45.5%), who worked (18.2%), who had a rented home (36.4%), who had health insurance (50%) and who used a car as a means of transportation (50%). In addition, there was a decrease in mothers who had only one child (27.3%), who practiced leisure activities (45.5%), who had health insurance (50%), who underwent therapy (9.1%), who received only one minimum wage (27.3%) and who received benefits (72.7%).

Table 1- Characterization of the sociodemographic profile of mothers in the first data collection. Goiânia, GO, Brazil, 2019.

City	n	%
Goiânia and Metropolitan Region	12	54,5
Other	10	45,5
Schooling		
Incomplete high school	2	9,1
Complete high school	10	45,5
Incomplete elementary education	4	18,2
Incomplete higher education incomplete	4	18,2
University degree completed	2	9,1
Civil Status		
Married	12	54,5
Divorced	1	4,5
Single	9	40,9
Relay		
No	13	59,1
Yes	9	40,9
No. of children		
1	8	36,4
2	7	31,8
3 or more	7	31,8
Leisure activity		
No	8	36,4
Yes	14	63,6
Health Insurance		
No	13	59,1
Yes	9	40,9
Therapy		
No	19	86,4
Yes	3	13,6
Family Income (minimum wage)		
1,0	9	40,9
1,5 to 3,0	13	59,0
Currently working		
No	19	86,4
Yes	3	13,6
Home		
Rented	7	31,8
Transferred	4	18,2

Own	11	50,0
Benefit		
No	5	22,7
Yes	17	77,3
Transportation		
Car	9	40,9
Bus	11	50,0
Van	2	9,1

n = absolute frequency; % = relative frequency

Source: Survey data (2019)

Table 2 describes the profile of the children at the first collection. The children had a mean age of 3.83 ± 0.58 years, while the cranial perimeter z-score had a mean of -3.49 ± 1.08 , which represents severe microcephaly.

Table 2- Characterization of the children's profile in the first data collection. Goiânia, GO, Brazil, 2019.

Gender	n	%
Female	14	63,6
Male	8	36,4
Classification of Microcephaly at birth		
Absent	2	9,1
Light	4	18,2
Grave	14	63,6
Not informed	2	9,1
GMFCS-LEVEL		
III	1	4,5
IV	2	9,1
V	18	81,8
Not informed	1	4,5
Physiotherapy		
No	1	4,5
Yes	21	95,5
Speech therapy		
No	1	4,5
Yes	21	95,5
Occupational therapy		
No	4	18,2
Yes	18	81,8

n = absolute frequency; % = relative frequency

Source: Survey data (2019)

In the second collection, there was a decrease in children who underwent physiotherapy (68.2%), speech therapy (13.6%) and occupational therapy (45.5%).

Table 3 compares the domains and total score of informal caregiver burden according to the QASCI instrument between the first and second data collection. The most affected domain in the first collection was financial burden, and in the second, mechanism of effectiveness and control. The domains of effectiveness and control mechanism and satisfaction with the role and the family member showed an increase in scores in the second collection, which indicates a worsening of the burden in these aspects. On the other hand, the financial overload domain decreased, indicating an improvement.

Table 3- Comparison of care overload using the QASCI between the first and second data collection. Goiânia, GO, Brazil, 1019 and 2020.

	Collection		p*
	First	Second	
Emotional overload	30,40 ± 27,16	32,39 ± 18,06	0,77
Implications for personal life	30,06 ± 16,61	32,74 ± 13,52	0,42
Financial overload	55,68 ± 29,31	25,57 ± 20,59	<0,01
Reactions to demands	23,41 ± 27,75	18,64 ± 13,82	0,75
Effectiveness and control mechanism	24,24 ± 20,40	34,09 ± 19,40	0,04
Family support	23,86 ± 27,52	32,95 ± 23,95	0,20
Satisfaction with role and family member	1,36 ± 4,41	11,14 ± 11,54	<0,01
Total score	27,00 ± 13,14	26,79 ± 10,72	0,93

*Wilcoxon test (Mean ± Standard Deviation)

Source: Survey data (2019 and 2020)

DISCUSSION

The mothers of children with CZVS showed greater burden in the first data collection in the financial burden domain. Financial difficulties and uncertainties about the economic future are aspects that are part of this domain and were compromised in this sample. A child with a disability directly impacts the mothers' job offer, in addition to generating high financial expenses due to the use of various medications, transportation to rehabilitation centers and therapies.¹⁷ All this causes a financial and occupational burden, preventing the mother from having a job to be

able to fully care for this child. This reality was observed in this study, since 100% of the mothers in the first collection are the main caregivers, 86.4% of them did not work and 77.3% needed to receive government aid and, even with this aid, the family income of 40.9% of the families was only one minimum wage.

In the second collection, there was an improvement in the financial burden domain. One hypothesis for this finding is the increase in the number of mothers who worked (18.2%) and who received more than one minimum wage (72.6%). However, there was a decrease in mothers receiving social benefits. This aid, called Continuous Cash Benefit (BPC), corresponds to a monthly minimum wage for people with disabilities who prove that they have no means of providing for themselves or their family. In order for a person with disabilities to receive it, the per capita family income must be less than ¼ of the minimum wage¹⁸, still not enough to meet all expenses. In addition, it is important to highlight that most of the jobs held by these mothers are informal, since the child demands a lot of time and disposition for its care, preventing these mothers from working an extensive working day, which reflects in a lower salary. In addition, a formal job could imply the cancellation of the BPC, preventing many mothers from looking for jobs with a formal contract.

There was a worsening of the effectiveness and control mechanism domain in the second evaluation, being the most affected in this collection. This domain encompasses factors such as time management, ability to continue with the care of the family member and knowledge about this care. It is believed that this worsening may have been due to the fact that the numerous therapies of the children were carried out during a period online, increasing the responsibility of the mothers. In addition, the pandemic period demanded too much from these mothers, further preventing them from practicing self-care. In addition, according to the clinical evolution of CZVS, the demands of children change over the years, since symptoms worsen, with a higher frequency of seizures, dysphagia, respiratory and gastrointestinal disorders¹⁹, which requires continuous improvement of care for this child.

The domain satisfaction with the role and the family member was the least affected in the second collection, however, it showed a worsening in relation to the first. Aspects such as caregiver well-being, family member gratitude, satisfaction with manifestations and indications of this gratitude, greater proximity between family members and high self-esteem due to this care are addressed in this domain. One hypothesis for the results presented is the decrease in the psychological support of mothers, where only 9.1% of them underwent therapy. It is believed that another important aspect for this domain to have worsened is due to the fact that 81.8% of the children were classified as GMFCS level V, which indicates severe limitations in head and trunk control, requiring extensive physical help.²⁰ A study that followed the evolution of the motor function of children with CZVS for a minimum interval of 6 months, identified that in the third year of life most did not improve this function and those of GMFCS level V had no significant changes; that is, they were probably close to the maximum potential of functionality.²¹

A limitation of this research was the small sample size. However, this study is important because it is innovative, since it addressed physical, emotional and social aspects of a little-studied population, in addition to analyzing these parameters in a pandemic period, investigating the impacts suffered and enhanced by this phenomenon.

CONCLUSION

The study showed that there was an improvement in the care burden of mothers of children with CZVS in relation to the financial aspect and a worsening in the mechanism of efficacy and control and satisfaction with the role and the family member. The effectiveness and control mechanism domain was the most affected in the second data collection.

Currently, care is very child-centered. However, mothers are fundamental in this process, and it is necessary to support this group at the same time. The family support network should be strengthened and specialized care should be ensured by a multiprofessional team. Psychotherapeutic support is important and should occur indefinitely. Public policies aimed at financial support are also essential. The creation of specialized workshops so that these mothers can work from home would be transformative, allowing them to supplement their income.

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