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Factors related to the quality of life of mothers of children with Congenital Zika Virus Syndrome

Fatores relacionados à qualidade de vida de mães de crianças com Síndrome Congênita do Zika Virus

Factores relacionados con la calidad de vida de madres de niños con Síndrome Congénito del Virus Zika

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ABSTRACT

Objective: To relate sociodemographic and clinical aspects to the quality of life of mothers of children with Congenital Zika Virus Syndrome.

Method: Cross-sectional analytical study, conducted in a rehabilitation center in Goiânia, central region of Brazil. A sociodemographic and clinical profile questionnaire and the World Health Organization Quality of Life were used. Data analysis was performed using the Mann-Whitney tests; Kruskal-Wallis, followed by Dunnett's Post hoc; and Spearman's correlation.

Results: The sample consisted of 30 mothers of children with Congenital Zika Virus Syndrome, with a mean age of 30.57 ± 6.67 years. Mothers who had a partner, leisure activity, who used a car as a means of transport and who had a child with congenital syndrome with microcephaly had a better quality of life ($p<0,05$).

Conclusion: The quality of life of these mothers was related to sociodemographic and clinical aspects, which suggests the need for more specific public policies for this population.

Keywords: Quality of life. Zika virus. Caregivers. Mothers.

RESUMO

Objetivo: Relacionar aspectos sociodemográficos e clínicos com a qualidade de vida de mães de crianças com Síndrome Congênita do Zika Vírus.

Método: Estudo transversal analítico, realizado em um centro de reabilitação de Goiânia, região central do Brasil. Foram utilizados um questionário de perfil sociodemográfico e clínico e o *World Health Organization Quality of Life*. A análise dos dados foi realizada por meio dos testes Mann-Whitney; Kruskal-Wallis, seguido do Post hoc de Dunnett e correlação de Spearman.

Resultados: A amostra foi constituída de 30 mães de crianças com Síndrome Congênita do Zika Vírus, com média de idade de 30,57 ± 6,67 anos. As mães que tinham companheiro, atividade de lazer, que utilizavam carro como meio de transporte e que tinham filho com a síndrome congênita com microcefalia, tiveram melhor qualidade de vida ($p<0,05$).

Conclusão: A qualidade de vida dessas mães teve relação com aspectos sociodemográficos e clínicos, o que sugere necessidade de mais políticas públicas específicas para esta população.

Palavras-chave: Qualidade de vida. Zika vírus. Cuidadores. Mães.

RESUMEN

Objetivo: Relacionar aspectos sociodemográficos y clínicos con la calidad de vida de madres de niños con síndrome congénito del virus del Zika.

Método: Estudio analítico transversal, realizado en un centro de rehabilitación en Goiânia, región central de Brasil. Se utilizó un cuestionario de perfil sociodemográfico y clínico y el *World Health Organization Quality of Life*. El análisis de los datos se realizó mediante las pruebas de Mann-Whitney; Kruskal-Wallis, seguida de Posthoc de Dunnett; y correlación de Spearman.

Resultados: La muestra estuvo conformada por 30 madres de niños con síndrome congénito del virus del Zika, con una edad promedio de 30.57 ± 6.67 años. Las madres que tenían pareja, actividad de ocio, que usaban el automóvil como medio de transporte y que tenían un hijo con síndrome congénito con microcefalia tenían una mejor calidad de vida ($p <0,05$).

Conclusión: La calidad de vida de estas madres se relacionó con aspectos sociodemográficos y clínicos, lo que sugiere la necesidad de políticas públicas más específicas para esta población.

Palabras clave: Calidad de vida. Virus Zika. Cuidadores. Madres.

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INTRODUCTION

In mid-2015, Brazil recorded an increase in cases of microcephaly in newborns, confirming the relationship with Zika virus infection(1). This virus belongs to the *Flavivirus* family, transmitted by *Aedes Aegypti*(2). From 2015 to November 2020, the Ministry of Health (MH) reported 3,563 confirmed cases of congenital syndrome associated with Zika virus infection and other infectious etiologies(3).

Transplacental transmission from the mother infected by the virus can result in a set of signs and symptoms in the child(4), which is called Congenital Zika Virus Syndrome (CZVS). Children with this syndrome have mild to severe sequelae, varying with the level of brain impairment. The main alterations are microcephaly, cerebral atrophy(5), diffuse calcifications, ventriculomegaly, dysgenesis of the corpus callosum, hypoplasia of the trunk and cerebellum, hearing and visual system impairment, abnormal muscle tone and irritability(6). The absence of microcephaly or subtle neuroimaging findings does not exclude the possibility that the child has been affected by Zika virus(7).

The mother is the most affected in the process of raising a child with a disability, as she changes her routine to provide the care that the child needs(8). After diagnosis, the family changes its dynamics to follow the child's consultations and therapies. Mothers often leave their jobs, reduce leisure and social activities and lose their personal identity by living for their disabled child(9).

The care for a person with a chronic and disabling disease at home reflects negatively on the quality of life of their caregivers, as it mainly affects their mental and physical health(10). The World Health Organization conceptualizes quality of life as "the individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns"(11). The quality of life of the mother is influenced by that of her children, as some do not perform pleasurable activities for themselves to dedicate themselves to the child's comprehensive care(9).

The CZVS is a public health issue that needs attention, as in the future there will be several children with sequelae resulting from this syndrome. Further studies are needed to understand the impact of CZVS on the quality of life of mothers, in order to support the creation of strategies that can minimize possible psychosocial problems and offer a support network.

Family support is often restricted and these mothers usually take on multiple tasks, such as housework and care for the child, husband and other children(12). This fact is confirmed in practice, when observing that mothers are the only companions during the rehabilitation process. Nowadays, there are few studies focusing on the quality of life of mothers of children with CZVS, most of which are qualitative. Only two quantitative studies were found in the database(13,14) which only portray the reality of the Northeastern population.

Given this context, the objective of this study was to relate sociodemographic and clinical aspects to the quality of life of mothers of children with CZVS who are in the rehabilitation process.

METHOD

Cross-sectional analytical study, conducted in a rehabilitation and readaptation center, located in Goiânia, central region of Brazil, from May to July 2019. The institution offers care exclusively by the Unified Health System (*Sistema Único de Saúde*), being recognized as a Specialized Rehabilitation Center (SRC) IV (rehabilitation of people with physical, visual, hearing, and intellectual disabilities) by the MH. It is a referral center that receives patients with CZVS from maternity hospitals of Goiânia and other cities in the country.

The study population consisted of mothers of children with CZVS. The following inclusion criteria were adopted: mothers of children undergoing rehabilitation process (individual therapies and/or early stimulation), with an exclusive and confirmed diagnosis of CZVS (C-reactive protein – PCR reagent for Zika virus and/or tomography image with abnormal characteristics of the syndrome). Caregivers who were not mothers and mothers of children with other associated neurological diseases were excluded. No sample calculation was performed, as the intention was to encompass the entire population. 30 participants remained eligible for the study.

Data collection was performed using three instruments: a sociodemographic and clinical assessment questionnaire for the mothers, a clinical assessment of the child and the World Health Organization Quality of Life instrument (WHOQOL-Bref).

The mothers' sociodemographic and clinical assessment questionnaires and the child's clinical assessment were elaborated by the researchers and were collected through interviews conducted with the mothers and complemented with analysis of electronic medical records, child and pregnant woman's card. Then, the mothers answered the WHOQOL-Bref questionnaire.

The sociodemographic and clinical variables related to the mothers were educational level (elementary, secondary and higher), marital status (with partner and without partner), number of children (1,2, 3 or more), family income (< 2 minimum wages, > 2 minimum wages), means of transport (car, bus, others), residence (rented, owned, given), social benefit (no, yes), worked before the child was born (no, yes), currently works (no, yes), leisure activity (no, yes, which), pregnancy (unexpected, planned) and chronic disease (no, yes). Changes with slow and long-lasting progression, silent or symptomatic were considered chronic disease(15).

The clinical variables of the children were type of delivery (cesarean section, normal), classification of microcephaly (absent, mild, severe), seizure (yes, no), arthrogryposis (yes, no), spasticity (yes, no), irritability (yes, no), visual alterations (yes, no), hearing alterations (yes, no), individual therapies (physical therapy, occupational therapy, speech therapy), weight, height, Apgar and head circumference at birth, and gestational age.

The WHOQOL-Bref assesses quality of life, is composed by 26 questions, two on general quality of life and general health, and the others representing 24 facets, distributed into four domains: physical, psychological, social relationships and environment(16). Each question generates an answer, with scores ranging from 1 to 5 according to the degree of satisfaction, with 1 being the worst result and 5 being the best, except for questions 3, 4 and 26, where the score is inverse. For the analysis of the WHOQOL-Bref questionnaire, scale values from 4 to 20 points were transformed proportionally to values from 0 to 100 in each domain and general quality of life. The higher the score, the better the quality of life(17).

The head circumference z-score was generated by the Intergrowth 21 calculator, as it presents values to assess preterm and full-term babies, with greater confidence in classifying the type of microcephaly(18,19).

The collected data were initially plotted in a spreadsheet using the Excel software (2013) and later analyzed with the support of the Statistical Package for Social Sciences (SPSS), version 23.0.

The characterization of the sociodemographic and clinical profile of the mothers and the child's clinical profile was performed using absolute (n) and relative (%) frequency for categorical variables; mean and standard deviation, median, minimum and maximum for continuous variables. In this study, non-parametric statistical tests and techniques were applied, as verified using the Shapiro-Wilk normality test. The comparison of quality of life (WHOQOL-bref) with the exploratory variables was performed using the Mann-Whitney and Kruskal-Wallis tests, followed by Dunnett's Post hoc analysis. Spearman's correlation was used to assess the relationship between the mothers' age and the child's current age with quality of life scores. In all analyses, the significance level adopted was 5% ($p < 0.05$).

The study was approved by the Committee for Ethics in Research on Human Beings of the *Pontifícia Universidade Católica de Goiás* (PUC Goiás), under opinion no. 3.237,062, approved in April 2019, complied with Resolution no.466, of December 12, 2012, from the National Health Council and the Free and Informed Consent Form was obtained from all participants.

RESULTS

At the time of data collection, the rehabilitation center had 37 children diagnosed with CZVS undergoing rehabilitation process (individual therapies and/or early stimulation). Seven mothers who did not want to participate in the study were excluded, with 30 mothers of children with CZVS remaining eligible. The age of the participants ranged from 19 to 42 years, with a mean of 30.57 ± 6.67 years.

Most mothers had completed high school, without partner, had more than one child in addition to the child with CZVS, had a family income of less than two minimum wages (including the government benefit), used the bus as a means of transport, had their own residence and received government benefit. Most reported not currently working, but before the child's birth with CZVS they worked. Only half had leisure activities (30% outings and 20% visiting relatives' homes). Most did not take turns caring for the child with CZVS with another person, had no chronic disease, did not undergo psychological therapy and the pregnancy was unexpected (Table 1).

A minority had health insurance plan (33.3%) and the insured was the child with CZVS. All mothers were infected with Zika virus in the first six months of pregnancy, mainly until the fourth month (90%) and underwent complete prenatal care as recommended by the MH.

Children with CZVS were aged between 1.1 and 3.6 years, with a mean of 2.4 ± 0.6 years and most were female (63.3%). It is observed in Table 2 that most children were born through cesarean section delivery and had severe microcephaly at birth. It is important to highlight that 13.3% of the children did not have microcephaly. Regarding the clinical changes of the children described in the medical records, most had convulsive crises, spasticity, irritability, and visual alterations; and a minority had arthrogryposis and hearing disorders. Most children underwent individualized Physical Therapy, Occupational Therapy and Speech Therapy.

Table 3 presents clinical characteristics of children with CZVS, in relation to the time of birth delivery (height, weight, Apgar 1st and 5th minute, gestational age, head circumference and z-score).

Table 1 – Characterization of the sociodemographic and clinical profile of mothers of children with Congenital Zika Virus Syndrome – Goiânia, GO, Brazil, 2019

Variables	N	%
Education		
Elementary	5	16.7
Secondary	18	60.0
Higher	7	23.3
Marital Status		
With partner	13	43.3
Without partner	17	56.7
Children		
1	10	33.3
2	10	33.3
3 to 5	10	33.3
Family Income *		
< 2 wages	17	56.7
2 to 3 wages	13	43.3
Transport		
Car	10	33.3
Bus	17	56.7
Other	3	10.0
Residence		
Rented	9	30.0
Given	5	16.7
Owned	16	53.3
Benefit		
No	6	20.0
Yes	24	80.0
Worked before the child was born		
No	6	20.0
Yes	24	80.0

Table 1 – Cont.

Variables	N	%
Currently works		
No	25	83.3
Yes	5	16.7
Leisure activity		
No	15	50.0
Yes	15	50.0
Relay care		
No	19	63.3
Yes	11	36.7
Chronic disease		
No	28	93.3
Yes	2	6.7
Psychological therapy		
No	26	86.7
Yes	4	13.3
Pregnancy		
Unexpected	16	53.3
Planned	14	46.7

n = absolute frequency; % = relative frequency
*Minimum wage at the time of data collection: BRL 998.00
Source: Research data, 2019.

Table 4 describes the domains and total score of quality of life according to the WHOQOL-bref instrument. The social and physical domains had better means and the environment domain the worst.

Table 5 compares the sociodemographic variables of mothers and clinics of children with the quality of life of mothers. It is observed that mothers who have a partner had better quality of life in the psychological and social domains and in the total score of the WHOQOL-bref than those without a partner. Mothers who have leisure activities had better quality of life in the psychological and environmental domains and in the total score than those who do not have leisure activities. Mothers who use a car as a means of transport had a better quality of life in the environment domain than those who use buses. Mothers of children with severe microcephaly had a better quality of life in the environment domain than those who did not.

There was no relationship between the variables: education, family income, currently working, relay care, health insurance plan, social benefit, psychological therapy, planned pregnancy, convulsive seizure, irritability, and the mothers' quality of life. There was no correlation between the age of mother and child at the time of data collection and the mothers' quality of life.

Table 2 – Clinical characteristics of children with Congenital Zika Virus Syndrome – Goiânia, GO, Brazil, 2019

Variables	N	%
Childbirth		
Cesarean section	21	70.0
Natural	9	30.0
Classification of microcephaly		
Absent	4	13.3
Mild	7	23.3
Severe	19	63.3
Convulsive seizures		
No	11	36.7
Yes	16	53.3
Not informed	3	10.0
Arthrogryposis		
No	6	20.0
Yes	2	6.7
Not informed	22	73.3
Spasticity		
No	1	3.3
Yes	27	90.0
Not informed	2	6.7
Irritability		
No	7	23.3
Yes	15	50.0
Not informed	8	26.7
Visual alterations		
No	6	20.0
Yes	22	73.3
Not informed	2	6.7

Table 2 – Cont.

Variables	N	%
Hearing alterations		
No	23	76.7
Yes	4	13.3
Not informed	3	10.0
Physical Therapy		
No	1	3.3
Yes	29	96.7
Speech Therapy		
No	3	10.0
Yes	27	90.0
Occupational Therapy		
No	4	13.3
Yes	26	86.7

n = absolute frequency; % = relative frequency
Source: Research data, 2019.

Table 3 – Clinical characteristics of children with Congenital Zika Virus Syndrome at birth delivery – Goiânia, GO, Brazil, 2019

Variables	Mean	Standard Deviation	Median	Minimum	Maximum
Weight (g)	2522.8	614.3	2655.0	1140.0	3595.0
Height (cm)	46.2	3.5	47.0	38.0	52.0
Apgar 1st minute	8.0	1.1	8.0	6.0	10.0
Apgar 5th minute	9.3	0.7	9.0	7.0	10.0
Gestational age (weeks)	37.9	2.0	38.0	34.0	42.0
Head circumference (cm)	28.7	2.3	29.0	22.5	34.0
Head circumference z-score	-3.30	1.1	-3.5	-5.06	0.08

Source: Research data, 2019.

Table 4 – Description of domains and total score of quality of life of mothers of children with Congenital Zika Virus Syndrome – Goiânia, GO, Brazil, 2019

Domains	Mean	Standard Deviation	Median	Minimum	Maximum
Physical	68.0	18.6	71.4	7.1	100.0
Psychological	61.5	16.3	62.5	16.7	95.8
Social	68.3	21.3	75.0	16.7	100.0
Environment	51.6	17.1	51.6	21.9	90.6
Total score	62.3	13.3	64.1	37.5	96.6

Source: Research data, 2019.

Table 5 – Comparison of quality of life in different sociodemographic profiles and severity of microcephaly – Goiânia, GO, Brazil, 2019

Variables	Physical	Psychological	Social	Environment	Total score
Marital Status*	p = 0.57	**p = 0.04**	**p = 0.04**	p = 0.45	**p = 0.03**
With partner	71.2 ± 16.7	68.6 ± 12.9	77.6 ± 16.8	54.6 ± 16.3	68.0 ± 11.7
Without partner	65.5 ± 20.0	56.1 ± 16.8	61.3 ± 22.0	49.3 ± 17.8	58.1 ± 13.2
Leisure activity*	p = 0.09	**p = 0.03**	p = 0.07	**p = 0.01**	**p< 0.001**
No	61.9 ± 20.6	55.8 ± 15.7	60.6 ± 23.9	43.3 ± 13.8	55.4 ± 10.9
Yes	74.0 ± 14.5	67.2 ± 15.3	76.1 ± 15.4	59.8 ± 16.3	69.3 ± 12.1
Transport**	p = 0.55	p = 0.36	p = 0.82	**p = 0.01**	p = 0.14
Car	70.7 ± 19.9	65.4 ± 16.4	66.7 ± 24.2	**62.8 ± 15.6a**	66.4 ± 15.8
Bus	65.5 ± 18.6	59.3 ± 17.0	67.6 ± 16.9	**44.5 ± 12.8b**	59.2 ± 9.5
Other	72.6 ± 18.0	61.1 ± 13.4	77.8 ± 38.5	**54.2 ± 27.3a,b**	66.4 ± 23.1
Microcephaly**	p = 0.96	p = 0.77	p = 0.94	**p = 0.04**	p=0.64
Absent	69.6 ± 10.3	59.4±9.2	68.8±19.7	**35.2±9.0a**	58.2±7.0
Mild	67.9±15.0	64.9±14.6	67.9±27.0	**47.8±16,2a.b**	62.1±13.2
Severe	67.7±21.5	60.7±18.3	68.4±20.5	**56.4±16.6b**	63.3±14.6

*Mann-Whitney; **Kruskal-Wallis followed by Dunnett's Post hoc Test
a; b; a,b: Equal letters indicate that there was no significance between the groups
Source: Research data, 2019.

DISCUSSION

Mothers of children with CZVS had worse quality of life in the environment domain and better in the social and physical domains. Mothers with partner, who have leisure activities, who use a car as a means of transport and who have a child with CZVS with severe microcephaly had better quality of life.

The most compromised domain of the quality of life of the mothers in this study was the environment. Research conducted in Sergipe with nine mothers of children with microcephaly due to presumed Zika virus infection, who were in the immediate postpartum period, the environmental and psychological domains were the most affected(14). The environment domain assesses the physical environment, transport, physical safety and protection, opportunity to acquire new information and skills, home environment, financial resources, participation and opportunities for recreation/leisure, health and social care(11). It is noteworthy that the minimum and maximum age of mothers was approximated (18 to 39 years old) and differed regarding the age of the children(14). During the children's first year of life, the nine mothers were reassessed, the quality of life remained poor and the environment domain was the most compromised, similar to the present study(13).

A possible hypothesis of the divergence found with the first study conducted in Sergipe is the stage in which these mothers were. In the postpartum period, psychological demands are greater and as the child gets older, the needs, for example, for specialized care, can compromise the mother's quality of life regarding the environment. A study carried out with 23 parents of children with microcephaly caused by Zika virus indicates that, after the child's birth, there were changes in the family context, there was an increase in economic expenses, one of the parents left his job to dedicate himself fully to the care of the disabled child, which resulted in increased stress and anxiety, need for hospital medical treatment and decreased leisure activity(12).

Women with partner had better quality of life in the psychological and social domains. Another study with families that have children with CZVS points out that there was a family readjustment to provide the necessary care for the new member and the women stated that they found in their partners the aid and support they needed to deal with the diagnosis of their children(20). Mothers, as they are the most affected by the child's diagnosis, tend to look for support to adapt to reality. Thus, family support is essential as it provides a support network and improves the quality of life(21).

It is interesting that the relay in the care of children with CZVS is not related to the mothers' quality of life. The simple presence of the partner is an important factor for emotional and social support. Spousal support for women who have a child with microcephaly caused by Zika virus is important in terms of providing more security for the woman to share her problems, relieving the stress of the daily routine of caring for the child(22).

Women who have leisure activities had better quality of life in the psychological and environmental domains. Data from a study conducted with 33 caregivers of children with microcephaly caused by Zika virus indicate that caregivers (especially mothers) are the most affected, with radical changes in their daily routines, putting their needs in the background, such as leisure, work and dreams(22). This finding shows the importance of public policies that provide access to leisure activities for this population. It stands out that half of the mothers do not have any leisure activities, that is, they are fully dedicated to child care.

Women who use a car as a means of transport had a better quality of life in the environment domain. The use of a car facilitates the family routine to attend consultations at the correct time, provides freedom, independence, comfort and safety to transport people with physical disability(23). The choice to use their own vehicle is linked to the low quality of Brazilian public transport, often not having the necessary adaptation to be used by a wheelchair user or people with reduced physical mobility. In this way, the car also guarantees agility in time and easy access to certain places(24). Unfortunately, only a small part of the sample (33.3%) uses a car as a means of transport, as observed in a previous study with 41 caregivers of children with microcephaly caused by Zika virus in the Northeast Region(25).

In 2003, it was created Law No. 10.690, which allows the purchase of a new vehicle, being a domestic and passenger car, with a 30% discount on the Tax on Industrialized Products, limited to a value of up to R$70,000.00, for people with a disabling disease or some type of disability (visual, motor, severe or profound mental, autistic) or by their legal representative(26). Despite the creation of the law, it is not enjoyed by the entire population that has this right, due to the large bureaucracy and the need for several documents, medical reports and exams that prove whether the individual fits the requirements to receive the benefit.

Women who have children with severe microcephaly had better quality of life in the environment domain compared to those without microcephaly. This fact, at first, was not expected, since the literature indicates that the smaller the head circumference, the greater the child's impairment(27). It is important to highlight that a small portion of the sample (13.3%) did not have microcephaly, which may have influenced the comparative analysis between groups.

A hypothesis that was refuted in the study refers to the lack of relationship between the variables family income and psychological therapy and the mothers' quality of life. As for income, this was possibly due to the homogeneity of the sample, being low-income women, who depend on a social benefit, and who, regardless of receiving less than two or even three minimum wages, proved to be insufficient for their need. Regarding psychological therapy, only 13.3% were followed up in this service, which may have been a limitation in this analysis.

The limitation of this study is related to the sample size, since it is restricted to a portion of mothers of children with CZVS who undergo rehabilitation treatment and not the entire population of mothers of children with CZVS who live in the capital of Goiás. But it is important to highlight that this sample included almost all mothers of children who undergo rehabilitation treatment at a reference center in the care of this population in the Midwest Region of Brazil. It is suggested that analytical research to be conducted to investigate factors related to quality of life, as well as longitudinal studies, with larger samples that can follow the changes in the quality of life of mothers as these children grow and require new demands.

CONCLUSION

The study showed that the most compromised domain of quality of life for mothers of children with CZVS was the environment; and that mothers who had a partner, leisure activity, who used a car as a means of transport and who had a child with CZVS with severe microcephaly had better quality of life.

These mothers live in a context of social vulnerability, as most are low-income, need social benefits to supplement their family income and depend on the care provided by the public health network. Given the above, it is believed that public policies can improve the quality of life of these mothers, especially in relation to the environment. It is essential to facilitate the access of this population to leisure activities, provide quality public transport, reduce bureaucracy in the acquisition of new vehicles and improve accessibility.

The findings of this study reinforce the importance of biopsychosocial care, with attention and reception of these mothers by the multidisciplinary team. It is highlighted the fundamental role of nurses in the training and autonomy of these women, so that they feel safe and confident in the role of caregivers, offering guidance on bathing, diet administration, feeding tubes hygiene, position changes, prevention of pressure ulcers, dressings, medication administration and how to act in the face of a convulsive seizure.

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