

The other victims: quality of life of mothers/caregivers of children with congenital Zika Virus syndrome

As outras vítimas: qualidade de vida das mães/responsáveis por crianças com síndrome congênita do Vírus Zika

DOI:10.34117/bjdv8n7-024

Recebimento dos originais: 23/05/2022

Aceitação para publicação: 30/06/2022

Maria das Neves Figueiroa

Doutora em Biologia Celular e Estrutural pela Universidade Estadual de Campinas (UNICAMP)

Institution: Faculdade de Enfermagem Nossa Senhora das Graças

Address: Rua Arnóbio Marques, 310, Santo Amaro, Recife - PE

E-mail: neves.figueiroa@upe.br

Lucilene Aguiar

Doutora em Ciências da Saúde pela Universidade de Pernambuco (UPE)

Institution: Faculdade de Enfermagem Nossa Senhora das Graças

Address: Rua Arnóbio Marques, 310, Santo Amaro, Recife - PE

E-mail: lucilene.rafael@upe.br

Maria Lucia Menezes

Doutora em Saúde da Criança e do Adolescente pela Universidade de Pernambuco (UPE)

Institution: Faculdade de Enfermagem Nossa Senhora das Graças

Address: Rua Arnóbio Marques, 310, Santo Amaro, Recife - PE

E-mail: maria.luciamenezes@upe.br

Gabriela Diniz Militão de Albuquerque

Graduação em Enfermagem pela Faculdade de Enfermagem Nossa Senhora das Graças, Universidade de Pernambuco (FENSG/UPE)

Institution: Faculdade de Enfermagem Nossa Senhora das Graças

Address: Rua Arnóbio Marques, 310, Santo Amaro, Recife - PE

E-mail: gabi.dmilitao@gmail.com

Jeisa Barbosa Diniz

Graduação em Enfermagem pela Faculdade de Enfermagem Nossa Senhora das Graças, Universidade de Pernambuco (FENSG/UPE)

Institution: Faculdade de Enfermagem Nossa Senhora das Graças

Address: Rua Arnóbio Marques, 310, Santo Amaro, Recife - PE

E-mail: jeisa_diniz@hotmail.com

Maria Patrícia Nascimento Silva

Graduação em Enfermagem pela Faculdade de Enfermagem Nossa Senhora das Graças,
Universidade de Pernambuco (FENSG/UPE)

Institution: Faculdade de Enfermagem Nossa Senhora das Graças

Endereço: Rua Arnóbio Marques, 310, Santo Amaro, Recife - PE

E-mail: mariahpatriciah@hotmail.com

Fábia Lima

Doutora em Neurociências e Comportamento pela Universidade de Pernambuco (UPE)

Institution: Faculdade de Enfermagem Nossa Senhora das Graças

Address: Rua Arnóbio Marques, 310, Santo Amaro, Recife - PE

E-mail: fabia.lima@hotmail.com

ABSTRACT

Objective. Identify the best way to support mothers/caregivers of children with congenital Zika virus syndrome (CZS) through quality of life analysis. **Method.** Sample consisting of 57 mothers/caregivers of children diagnosed with microcephaly associated with CZS, interviewed in the State of Pernambuco, Brazil, in 2016. Cross-sectional study with a descriptive approach and assessment of quality of life using the instrument "The Pediatric Quality of Life Inventory 2.0 (PedsQL) – Family Impact Module." **Results.** The mothers/caregivers of children with CZS: a) were around 30 years old; b) lived in the Metropolitan Region of Recife (Região Metropolitana do Recife [Grande Recife]); and c) lost almost 50% of their quality of life after the birth of the children. **Conclusion.** The support network for children with microcephaly must seek to reduce the negative impact of motherhood via support for the preservation of the physical and mental integrity of mothers/caregivers.

Keywords: microcephaly, Zika Virus infection, quality of life, mother-child relationships.

RESUMO

Objetivo. Identificar a melhor forma de apoiar mães/ cuidadores de crianças com síndrome do vírus Zika congênito (CZS) através da análise da qualidade de vida. **Método.** Amostra composta de 57 mães/ cuidadores de crianças diagnosticadas com microcefalia associada à CZS, entrevistada no Estado de Pernambuco, Brasil, em 2016. Estudo transversal com abordagem descritiva e avaliação da qualidade de vida utilizando o instrumento "The Pediatric Quality of Life Inventory 2.0 (PedsQL) - Family Impact Module". **Resultados.** As mães/ cuidadoras de crianças com CZS: a) tinham cerca de 30 anos de idade; b) moravam na Região Metropolitana do Recife [Grande Recife]; e c) perderam quase 50% de sua qualidade de vida após o nascimento das crianças. **Conclusão.** A rede de apoio às crianças com microcefalia deve procurar reduzir o impacto negativo da maternidade através do apoio à preservação da integridade física e mental das mães/responsáveis.

Palavras-chave: microcefalia, infecção pelo Vírus Zika, qualidade de vida, relações mãe-criança.

1 INTRODUCTION

Since 2015, Brazil has been going through a triple epidemic of denguefever, chikungunya, and Zikafever, transmitted by the mosquito *Aedes aegypti*. Such infectious diseases are characterized by their unpredictable, explosive, highly transmissible nature, their relationship with environmental factors, the influence of human behavior, and the need for prevention and control at the public health level.¹

The recent introduction of the Zika virus in the Brazilian territory exposed the great risk of illness in a susceptible population, constituting an impact on public health, due to the high need for health surveillance and clinical care actions, as well as an economic and social impact, requiring interconnected health actions to respond to the event.¹

The detection of a change in the birth pattern of children with the symptom of microcephaly (neurological status in which the newborn's head is smaller when compared to the pattern of other newborn infants of the same sex and age) has triggered the alert to the authorities in October 2015 in the State of Pernambuco, Northeastern Brazil. The hypothesis of association between this malformation and the Zika virus infection has brought an unusual situation, communicated to the World Health Organization (WHO), where, based on the International Health Regulations, case verification was carried out and the risk of international dissemination was assessed.²

The historical prevalence of microcephaly recorded by the Ministry of Health (MoH) in Brazil was 0.5 per 10,000 live births. However, despite the possible under-registration of these data, the increased number of suspected cases (greater than 3,000), after the second half of 2015, started to represent an increase of about 20 times between the expected and the registered prevalence (from 1-2 for 20 cases per 10,000 live births) within the period.

The Zika virus infection has been known since the 1940s, with human cases recorded in countries in Africa, Asia, and Oceania. Urban Zika virus transmission encompasses species of the genus *Aedes* and other mosquitoes of the subgenus *Stegomyia*. In Brazil, *A. aegypti* females have been identified as the main vector. The known property of the Zika virus is characterized by benign behavior, low pathogenicity, and very low virulence and lethality. Little was known about its ability to cause severe neurological complications (Guillain-Barré syndrome) and its teratogenicity, which has been investigated in Brazilian cases. This hypothesis was strengthened by the necroscopic

finding of a strong concentration of viral material in the nervous tissue of stillborn infants affected by microcephaly.^{1,5,6}

The investigation of this public health issue has been the main mission of health and research agencies. In vitro studies have revealed the ability of the virus to infect neural progenitor cells, affecting cell cycle regulation and cell survival.⁷ Despite the findings, there are still epidemiological, clinical, entomological, and basic science questions to be answered.

Fetal abnormalities, in newly infected children, have been mapped to better outline aspects of the congenital Zika virus syndrome (CZS). Clinical findings include neurological and hearing manifestations, visual changes, and other neuroimaging findings.⁸ Adequacy in the definition of this syndrome will require time to monitor the affected children for further information collection.

The clinical status of these children entails, for the mothers/caregivers and their families, numerous constraints and changes, generating the need to adapt to a new reality. Having a child in need of special attention requires adapting the daily life and lifestyle of the mother and family, which is a comprehensive condition for the child's survival. It is necessary to see the growing need for care, due to the vulnerable nature of this newborn infant.⁹

This study aims to analyze the impact of this scenario on the quality of life of mothers/caregivers, who are characterized as *the other victims* of this public health emergency: they are not affected by the physical sequelae of CZS, but take the burden of infection in children.

The women interviewed in this study belong to the first generation of pregnant women infected with the Zika virus in Brazil. They were victims of an infection with teratogenic potential, hitherto unknown by health authorities and the scientific community. They lived moments of helplessness due to unpreparedness of the health field.¹⁰

The WHO defines quality of life as a person's perception of her/his life status in the context of culture and in the value system in which she/he lives and in relation to her/his goals, expectations, standards, and concerns.¹¹

The need to identify the best way to support family members of children with CZS has raised our interest in investigating the quality of life of mothers/caregivers and their families, followed up at a referral center in the State of Pernambuco.

2 METHODS

Cross-sectional, quantitative study with a descriptive approach, carried out in the first referral service for the care of children affected by CZS in Pernambuco. The Pediatric Outpatient Clinic of Infectious and Parasitic Diseases of the Oswaldo Cruz University Hospital, of the University of Pernambuco (Hospital Universitário Oswaldo Cruz, da Universidade de Pernambuco (HUOC/UPE), was the data collection site. Between October 2015 and February 2016, 340 children with congenital malformations were clinically followed up at this hospital unit, with 125 confirmed cases of CZS.

The study population consisted of 125 women, mothers/caregivers of children with confirmed diagnosis of CZS. The final sample consisted of 57 mothers who completed the assessment steps proposed in the study. The sample loss was due to refusals, small number of children provided with care per day at the specialized outpatient clinic, and simultaneous monitoring of children in other services.

Data collection took place between August and November 2016, through structured interviews. The questionnaire adopted was the Brazilian version of “The Pediatric Quality of Life Inventory 2.0 (PedsQL) – Family Impact Module,”¹² which assesses the impact of pediatric diseases on the quality of life of mothers/caregivers and family members. This instrument has 8 subscales, out of which 6 are aimed at assessing caregiving mothers regarding these aspects: physical (6 items), emotional (5 items), social (4 items), cognitive (5 items), communication (3 items), and concern (5 items); and 2 further subscales that measure family functioning through daily activities (3 items) and family relationships (5 items).

The scale has 5 Likert-type response options, ranging from “never” to “almost always,” where the items must be scored in each dimension and turned into a linear scale ranging from 0 to 100 (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better functioning (less negative impact). The PedsQL Family Impact Module is calculated by adding the scores of the 36 items divided by the number of items answered.¹²

For data analysis, a bank was built on the spreadsheet of the software *Microsoft Excel*, which was exported to the software *SPSS*, version 23. The sociodemographic profile, the housing status, the clinical status of children, and the consequences of the CZS were analyzed, based on the calculation of the percentages and the respective frequency distributions. To compare the percentages found in the levels of the factors assessed, the chi-square test was applied.

To assess quality of life, the scores for each domain of the instrument PedsQL were calculated. To assess the normality of the score, the Shapiro-Wilk test was applied. As the normality of the scores assessed was pointed out, Student's *t* test was applied to paired samples. Also, Pearson's correlation score was calculated, in order to determine the degree of correlation between the mother's personal quality of life score and the family function. All statistical conclusions were calculated considering a 5% significance level.

This research complied with the ethical precepts for research with human beings, according to the Declaration of Helsinki,¹³ as well as with the guidelines and standards that regulate research involving human beings, contained in Resolution CNS No. 466, enacted in December 12, 2012 in Brazil.¹⁴ The study was approved by the Research Ethics Committee of the University of Pernambuco (Universidade de Pernambuco [UPE]), under the Brazilian Certificate of Submission for Ethical Assessment (Certificado de Apresentação para Apreciação Ética [CAAE]) No. 55696416.8.3001.5191.

3 RESULTS

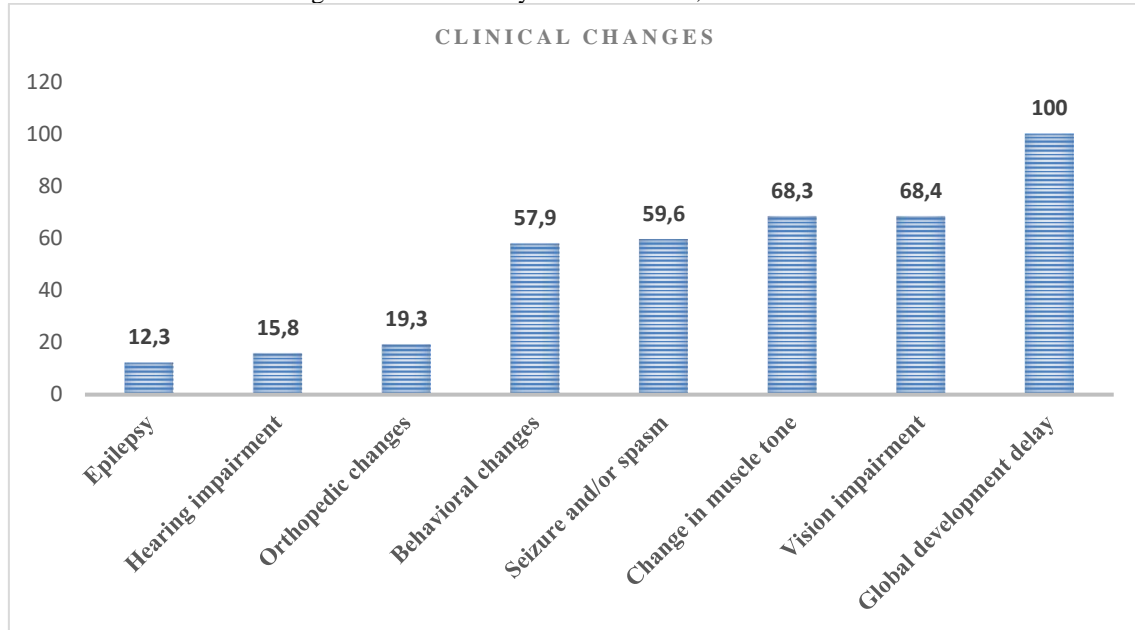
Regarding the 57 mothers interviewed, in sociodemographic terms there was a predominance of women in the age group from 30 to 39 years (45.6%), brown skinned (50.9%), with educational level up to complete High School (35.1%), living in a marriage-like relationship (43.9%), and housewives (43.9%). Family income corresponded to a minimum wage (approximately US\$ 280.00 at the time of the study), with an average of 4.4 people per family in the Metropolitan Region of Recife (Região Metropolitana do Recife [Grande Recife]).

The majority (68.4%) of the interviewees reported having a family with 2 to 4 children. They said to have been infected with the Zika virus in the first (47.4%) or second trimesters (26.3%) of pregnancy. The support of the child's parents and family members was informed by most women at the data collection time (78.9%).

As for the children, CZS mainly affected female newborn infants (54.4%), aged between 8 and 12 months within the research period, whose confirmation of CZS occurred shortly after birth (66.7%). Considering the child's health status, mothers reported that they showed between 4 and 7 bodily changes, including microcephaly.

Figure 1 illustrates the changes of greater and lesser proportions expected within this scenario of CZS in the study population, with an occurrence greater than 60.0% in changes such as global developmental delay, impaired vision, and change in muscle tone.

Figure 1. Zika virus syndrome. Recife, 2015-2016



The tables below show the scores in each domain of the quality of life scale formothers/caregivers of children affected by CZS, being scored from 0 to 100, considering that the higher the score, the better the quality of life of this mother/caregiver.

Table 1 shows the average and standard deviation of the quality of life score according to the domains and items of the instrumentPedsQL. Women report a greater impact and consequent decrease in their quality of life in the domains related to: “concerns” (average = 36.14 points), “daily activities” (average =39.77 points), and“emotional functioning”(average = 51.67 points). Among the items that stood out in each of these domains, the most compromising to the patients’ quality of life were: “concerns about medical treatment” (average = 15.35 points) and “concerns about side effects of medication” (average = 29.39 points).The difficulties to fulfilldaily activities are expressed in the items:“it is hard to find time to fulfill daily activities” (average = 30.70 points) and “fatigue has made it hard to finish doing housework”(average = 36.84 points).And feelings are expressed this way:“I feel anxious”(average = 29.82 points) and“I feel sad” (average = 39.91 points).

Table 1 Descriptive analysis of the quality of life score of women assessed according to domains and items. Recife, 2015-2016

Domain	Items	Statistic Assessed	
		Average	Standard Deviation
Physical Functioning	I feel tired during the day	31,14	26,84
	I feel tired when I wake up in the morning	58,77	36,44
	I feel too tired to do the things I like to do	46,93	37,22
	I have headaches	50,00	33,07
	I feel weakness in my body	69,74	35,27
	I feel nausea	91,67	16,59
	Total	58,04	17,93
Emotional functioning	I feel anxious	29,82	32,20
	I feel sad	39,91	30,93
	I feel angry	62,72	33,78
	I feel disappointed	64,04	38,39
	I feel helpless and hopeless	61,84	40,67
	Total	51,67	23,87
Social functioning	I feel isolated from other people	75,44	35,19
	It is hard for me to get help from other people	53,51	39,37
	It is hard for me to find time for social activities	43,86	39,89
	I feel that I lack energy for social activities	46,05	39,18
	Total	54,72	26,63
Cognitive Functioning	It is hard for me to keep my attention on things	54,82	36,73
	It is hard for me to remember what other people tell me	50,44	37,35
	It is hard for me to remember what I just heard	60,53	34,70
	It is hard for me to think fast	54,82	34,54
	It is hard for me to remember what I just thought	59,65	38,31
	Total	56,05	25,80
Communication	I feel that other people do not understand my family's situation	45,18	38,51
	It is hard for me to talk about my child's health status with others	66,67	39,34
	It is hard for me to tell doctors and nurses how I feel	61,84	41,75
	Total	57,89	27,84
Concerns	I worry if my child's medical treatment is working	15,35	21,52
	I worry about the side effects of my child's medication and treatment	29,39	39,84
	I worry about how other people will react to my child's health status	52,19	41,80
	I worry about how my child's illness affects other people in my family	75,00	36,60
	I worry about my child's future	8,77	18,60
	Total	36,14	19,89
Daily activities	Do family activities require more time and effort?	51,75	41,69
	Is it hard to find time to finish doing housework?	30,70	35,99
	Has tiredness made it hard to finish the housework?	36,84	36,63
	Total	39,77	32,66
Family relationships	Is there a lack of communication between people in your family?	64,91	38,92
	Are there conflicts between people in your family?	75,88	33,40
	Is it hard to make decisions together in your family?	60,53	40,63
	Is it hard to solve your family's problems together?	65,79	36,48
	Is there stress and tension between people in your family??	51,32	38,79
	Total	63,68	27,57

In all domains analyzed, items were identified where there was a loss of more than 50% of quality of life, except in the domains “cognitive functioning” and “family relationships.” The domains “concerns” and “daily activities” stand out as those with the highest indicators of impaired quality of life.

Table 2 analyzes the correlation between the mother’s quality of life score and the family function score. When assessing the correlation between them, the coefficient was positive ($r = 0.634$) and significant ($p < 0.001$), indicating that, with an increased quality in the “family function,” there is a significant increase in the mother’s quality of life, and vice versa. Generally, it is observed that the average mothers’ total quality of life is 52.72 points, i.e. with a loss of 47.8 points in the quality of life they could have.

Table 2 Descriptive and correlation analysis of the mother’s quality of life score, the family function score, and the total score, Recife, 2015-2016

Domain assessed on quality of life	Statistics assessed			Correlation	
	Average	Standard deviation	<i>p</i> value ¹	R	<i>p</i> value ²
The mother’s	55.29	17.72	0.826	0.634	<0.001
Family function	54.71	25.08			
Total	52.72	16.76	-	-	-

Notes: ¹*P* value of Student’s *t* test for paired samples. ²*P* value of Pearson’s correlation test.

Table 3 shows the average values and standard deviations of the scores related to the mother’s quality of life, to the domains “family function,” and “total quality of life,” correlating the values to the presence of problems related to CZS. Only the domains “family function” and “total quality of life” had relevant variables capable of changing the score. In the domain “family function,” the determining variables for the quality of life score were: number of problems resulting from CZS ($p = 0.012$), hearing impairment ($p = 0.008$), and epilepsy ($p = 0.040$).

Analyzing the quality of life scores in relation to the occurrence of certain types of health problems in children, it was found that there is a better quality of life in the domain “family function” when the child has 1 to 3 consequences of the syndrome (average = 66.28 points).

Hearing loss and the occurrence of epilepsy alter the quality of life of mothers/caregivers for the worse. In other words, there are better quality of life scores in “family function” for mothers/caregivers of children who did not have hearing impairment or suffer from epilepsy (average = 58.46 points and 57.25 points, respectively).

Table 3 also shows that hearing impairment significantly influences the total quality of life score ($p = 0.021$), with the group without impairment having the best quality of life (average = 54.90 points).

Table 3 Descriptive analysis of the mother's quality of life score, the family function score, and the total score, according to the presence of problems related to congenital Zika virus syndrome. Recife, 2017

Factor assessed	Mother's life		Family function		Total quality of life	
	Average±SD	p value ¹	Average±SD	p value ¹	Average±SD	p value ¹
Does your child have any problems as a result of the congenital Zika virus syndrome?						
1 to 3 problems	59.41±21.91	0.279 ¹	66.28±22.76	0.012¹	58.63±19.84	0.094 ¹
4 to 7 problems	53.22±15.12		48.93±24.43		49.76±14.38	
Vision impairment						
Yes	55.03±17.20	0.876 ¹	51.84±26.77	0.206 ¹	51.66±17.22	0.487 ¹
No	55.83±19.30		60.94±20.23		55.02±15.95	
Change in muscle tone						
Yes	55.73±16.08	0.807 ¹	52.60±23.62	0.410 ¹	52.39±14.87	0.850 ¹
No	54.52±20.64		58.33±27.62		53.27±19.97	
Convulsions and/or spasms						
Yes	52.43±16.91	0.140 ¹	49.91±24.05	0.078 ¹	49.41±15.27	0.069 ¹
No	59.51±18.41		61.82±25.39		57.61±17.98	
Behavioral changes						
Yes	52.42±16.39	0.155 ¹	51.04±23.08	0.197 ¹	49.73±14.69	0.115 ¹
No	59.22±19.05		59.77±27.28		56.83±18.79	
Deformity (clubfoot)						
Yes	56.59±12.44	0.788 ¹	55.40±23.01	0.921 ¹	53.41±10.75	0.839 ¹
No	54.97±18.86		54.55±25.78		52.55±17.99	
Hearing impairment						
Yes	46.39±14.81	0.101 ¹	34.72±23.77	0.008¹	41.05±12.76	0.021¹
No	56.95±17.85		58.46±23.71		54.90±16.61	
Epilepsy						
Yes	54.29±11.20	0.875 ¹	36.61±20.23	0.040¹	46.63±11.14	0.309 ¹
No	55.42±18.53		57.25±24.80		53.57±17.31	

Note: ¹P value of Student's t test for independent samples.

4 DISCUSSION

The results of this study made it possible to know some aspects of the profile, the physical and emotional burden on mothers/caregivers of children with CZS and verify these aspects in their quality of life.

The social and economic profile found in this study is consistent with a group of populations at risk and vulnerable, whose housing occurs in places with low coverage of basic sanitation and scarce water supply, providing a favorable environment for the high infestation of the vector that transmits the disease.¹⁵ Besides,¹⁶ such characteristics, like race, education, family income, and occupation are identified as factors that change the physical and mental status of the mother/caregiver, which may impact the care for children with CZS.

According to data from the MoH,⁵ the profile of women participating in this study corresponds to the majority of mothers and families that had children with sequelae resulting from maternal Zika virus infection. In Brazil, most of them came from families of less privileged economic classes, from mothers with low educational level, living in urban outskirts.

A study¹⁷ on the psychological adaptation of mothers whose children had cerebral palsy found that in those families who live in neighborhoods on the outskirts the quality of maternal life is lower. Attention was also drawn¹⁸ to the fact that, among mothers with lower socioeconomic levels, quality of life was reduced. In this study, the greatest interference in the perception of quality of life reported by mothers was associated with difficulties in access to transportation, infrastructure conditions in the neighborhood where they lived, and poor access to services that provide medical care. In families with low socioeconomic status, the physical problems of mothers are accentuated, due to difficulties in handling their children that result from housing conditions and difficulties in accessing public transport services.

Most of the mothers assessed in this study were from the Grande Recife. According to the so-called *epidemiological week*,¹⁹ the region had 43.1% of the births of children affected by CZS among the cases registered in the State of Pernambuco. A greater concentration of cases was also observed in the Regional Health Management Area I (Gerência Regional de Saúde I), corresponding to Greater Recife and Fernando de Noronha.

Neurological changes in children were observed after birth. At the time, the causes and the extent of the consequences were unknown, but it was already possible to claim

that those children would face many obstacles, as brain development had been severely affected by an infectious disease, which had not been defined, yet.

In the population under study, maternal infection occurred mainly within the first and second trimesters of pregnancy. The identification of the etiologic agent responsible for the infection occurred in January 2016, when the presence of genetic material from the Zika virus was found in the amniotic fluid of pregnant women.⁵ Later studies²⁰ confirmed that, sometimes, the Zika virus crosses the placenta and causes viral encephalitis, and it may trigger a varied degree of severity, with no control by the fetal immune system or by Zika antiviral antibodies.

The research findings are in line with the study carried out by the Ministry of Health,⁹ where it was stated that within the embryonic period, which corresponds to the time between the 3rd and 8th gestational weeks, the fetus has a higher risk of infectious complications. However, CZS cases also seem to show brain changes within the 2nd and 3rd trimesters of pregnancy.¹⁰

As for neurological changes, the findings pointed out that most children had a syndrome that brought together, on average, 4 to 7 changes – among which a global delay in neuro-psycho-motor development, impaired vision, change in muscle tone, seizures and/or spasms, and behavioral changes, making the condition more severe and leading to the need for more attention and care offered to mothers.

Congenital microcephaly can undergo several changes, the most common being intellectual disability, cerebral palsy, epilepsy, swallowing difficulty, anomalies in the vision and hearing systems, in addition to behavioral disorder (attention deficit hyperactivity disorder [ADHD] and autism).²¹

In the assessment of health-related quality of life, which addressed the physical, emotional, social, and cognitive functioning of the mothers/caregivers interviewed, it was possible to identify a low average quality of life score (52.2 points), with a loss of 47.8 points in the quality of life that they could have. It has been reported²² that factors observed in the mothers' lives, with a marked change in their role as caregivers, may determine the consequences on the quality of life of these women.

Studies on family impact and adjustment of parents of children diagnosed with congenital anomaly²³ show found similar results in terms of parents' quality of life. The existence of a child diagnosed with a deficiency or congenital anomaly in a family requires a series of healthcare procedures and requirements that, for parents and primary caregivers, can lead to the deterioration of well-being and quality of life at higher levels

of burden and vulnerability to stress, as well as to feelings of depression and sadness, devaluation and guilt, and symptoms of post-traumatic stress.

The analysis of results related to perception of the mother's quality of life considering the physical domain pointed out a clearer maternal exhaustion, with an emphasis on tiredness and lack of time to rest. Still concerning this physical aspect, another study²⁴ pointed out that the functional dependence of a child with cerebral palsy caused physical and emotional overload among family members, especially the mothers – who more often take care of their children.

Physical and psychological distress has been associated with impairments in the quality of life of mothers/caregivers of children with special needs. Some studies carried out with mothers of children with cerebral palsy demonstrated unwillingness to perform physical activities and to engage in social relationships, in addition to poor perception of health conditions, predisposition to stress, lack of knowledge about the children's disease, decreased mood, and trouble with social, family and professional life. A study²⁵ stated that maternal physical exhaustion is always high, regardless of the level of care and attention required by their children, and the fact that consequences in the domain "physical functioning" (fatigue, exhaustion), impaired social relationships (decrease in leisure activities, changes in relations to family members), and problems of an economic nature (financial difficulties) are also highlighted.²³

Assessing the domain "emotional functioning" showed great interference in the quality of life of the mothers/caregivers who participated in the study, with an emphasis on anxiety and sadness. Mothers and family members usually have few answers, many doubts and fears. Mothers accumulated anxiety due to the challenge of providing all the care needed by a baby whose malformation defies the public health field.⁵

The conceptual references that discuss aspects of motherhood and women's sexuality from a psychoanalytic and cultural viewpoint, with a view to grasping the meaning of having a child with special needs for a woman, constituted the object of another study²⁶ that describes how social needs based on the figure of the "good mother" intensify the insecurity that mothers of children with no special needs feel in face of their roles as "she mothers" and exacerbate the feeling of incapacity among the "she mothers" of malformed children. This is so because the birth of a child with special needs generates a series of reactions to what is unexpected among parents (which include periods of emotional crises and psychosocial adaptations).

The domain “communication” had a low score of contribution to quality of life. Studies reveal that this fact is due to difficulty of exposing the situation of a child affected by CZS to society, to the health team, and especially to the family. Many parents end up avoiding contact with other people for fear of rejection and shame.²⁷ On the other hand, it is noteworthy how hearing impairment or loss in children with CZS has been identified as a significant factor that affects the communication process, with an impact on the domain “family function” and decreased quality of life.

According to other studies,²⁸ human communication is key for quality of life, because an individual’s socialization process and search for autonomy occurs by means of it. Finding out that a child is deaf is usually regarded as a major disorder for the family, becoming a source of conflicts with repercussions for the entire family group, especially in terms of communication difficulties. Therefore, parents are expected to feel insecure and guilty. Several studies show that the level of stress is more evident in families of children with some special need, due to the specific care needed and the dependency relationship that is established between parents and their deaf children.

The component showing the greatest impact on the quality of life of mothers/caregivers was that regarding the concerns. This fact is justified by the complexity of the cases, the assistance required by these babies, and the need for care provided by a multidisciplinary team (pediatrician, neurologists and early stimulation practitioners, physiotherapist, occupational therapist, and speech therapist). Depending on the assessment, a six-month ophthalmological and auditory reassessment is necessary. All of these needs are a matter of concern.^{5,10,30}

A major aspect when assessing the quality of life of mothers/caregivers consists in the fact that the group reports a significant family support – an indicator observed in the assessment of most women who highlighted being able to rely on the help of their children’s fathers and/or her family members to care for their children, something which helps them to face the difficulties. This finding contributed positively when regarded as an indicator of quality of life. Holding hands, fathers and mothers have become stronger in face of the need to care for the growth of their children who cope with the consequences of a virus that has left the whole world on alert.

Another study²⁹ has shown that there is often a decrease in the support provided by society and family members to the mothers of children with neurological disorders, as they are socially isolated. However, when mothers have a good family relationship and family support, they are more available and report less emotional burden, regardless of a

child's motor impairment. Maternal support reflects a decrease in some health problems for the mother and more help to care for children.

Finally, it is worth noticing that members of the nuclear family had higher levels of impact than others on the care of people with chronic diseases and malformations. Some studies emphasize that, in the case of children, the burden of this function ends up falling on the mother/caregiver. Even with family support, it is a matter of gender: care arises from a cultural pattern that assigns to the mother the unconditional and, usually, exclusive role of providing all the attention that a sick child requires.

5 CONCLUSION

The results of this study have shown a profile of socially and economically vulnerable women, whose quality of life assessment standard has suffered a negative impact, with an almost 50% reduction in all domains analyzed.

Fear of what the future might hold for their children, concerns about the needs for care, and the guarantee of full access to the treatments required for the survival of their children significantly impacted the quality of life of mothers/caregivers.

This study has demonstrated that there is a need for specific and continued support for these women and the family members of children with microcephaly, relying on government action (mainly taken by the MoH), in order to provide the support that such families need in facing all aspects related to the treatment, monitoring, and growth of children.

We emphasize that mothers/caregivers, in general, have a worse quality of life, for this reason, we believe that they, although not neglecting the parents and other family members, should be the target of further clinical attention and greater support from social and mental support structures.

The scarcity of Brazilian studies on the population of caregivers and their quality of life, since most of the literature prioritizes patient assessment, justifies the encouragement of rather in-depth and continued study initiatives addressing the quality of life and mental health of mothers/caregivers of children with CZS, thus allowing for more informed and skilled action by the governments and practitioners at stake.

We believe it is worth mentioning some limitations of this research, which may justify some caution in the interpretation of results, like sample size and sampling procedure (by convenience), which may hinder the generalization of conclusions. Thus,

we suggest considering the assessment of mothers/caregivers of children followed up at other services and under different financial conditions in further investigations.

REFERENCES

1. Lima-Camara TN. Emerging arboviruses and public health challenges in Brazil. *Rev Saúde Pública*. 2016;50:36. <http://dx.doi.org/10.1590/S1518-8787.2016050006791>
2. World Health Organization. Revision of the International Health Regulations. Geneva: WHO; 2005.
3. Zika virus: a new global threat for 2016. *Lancet*. 2016;387:96. [https://doi.org/10.1016/S0140-6736\(16\)00014-3](https://doi.org/10.1016/S0140-6736(16)00014-3)
4. Schuler-Faccini L, Ribeiro EM, Feitosa IM, Horovitz DDG, Cavalcanti DPC, Pessoa AP, et al. Possible association between zika virus infection and microcephaly – Brazil, 2015. *MMWR Morb Mortal Wkly Rep*. 2016;65:59-62. <http://dx.doi.org/10.15585/mmwr.mm6503e2>
5. Brasil. Vírus Zika no Brasil: a resposta do SUS. Brasília (DF): Ministério da Saúde; 2017.
6. Musso D, Cao-Lormeau VM, Gubler DJ. Zika virus: following the path of dengue and chikungunya? *Lancet*. 2015;386:243-4. [https://doi.org/10.1016/S0140-6736\(15\)61273-9](https://doi.org/10.1016/S0140-6736(15)61273-9)
7. Tang H, Hammack C, Ogden SC, Wen Z, Qian X, Li Y, et al. Zika virus infects human cortical neural progenitors and attenuates their growth. *cell stem cell*. 2016;18(5):587-90. <https://doi.org/10.1016/j.stem.2016.02.016>
8. McCarthy M. Severe eye damage in infants with microcephaly is presumed to be due to Zika virus. *BMJ*. 2016;352:i855. <https://doi.org/10.1136/bmj.i855>
9. Brasil. Diretrizes de estimulação precoce: crianças de zero a 3 anos com atraso no desenvolvimento neuropsicomotor decorrente de microcefalia. Brasília (DF): Ministério da Saúde; 2016.
10. Eickmann SH, Carvalho MDCG, Ramos RCF, Rocha MAW, Linden VV, Silva PFS. Síndrome da infecção congênita pelo vírus Zika. *Cad Saúde Pública*. 2016;32(7):1-3. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-311X2016000700601&lng=pt&tlng=pt
11. Minayo MCS, Hartz ZMA, Buss PM. Qualidade de vida e saúde: um debate necessário. *CiêncSaúde Colet*. 2000;5(1):7-18. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232000000100002&lng=pt&tlng=pt
12. Scarpelli AC, Paiva SM, Pordeus IA, Varni JW, Viegas CM, Allison PJ. The Pediatric Quality of Life Inventory (PedsQL) family impact module: reliability and validity of the Brazilian version. *Health Qual Life Outcomes*. 2008;6:35. <http://dx.doi.org/10.1186/1477-7525-6-35>
13. Associação Médica Mundial. Declaração de Helsinki. Edinburgo: AMB; 2000.

14. Brasil. Resolução CNS n. 466, de 12 de dezembro de 2012. Brasília (DF): Ministério da Saúde; 2012.
15. Nunes J, Pimenta DN. The Zika epidemic and the limits of global health. *Lua Nova*. 2016;98:21-46. <http://dx.doi.org/10.1590/0102-6445021-046/98>
16. Macedo EC, Silva LR, Paiva MS, Ramos MNP. Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. *Rev Latinoam Enferm*. 2015;23(4):769-77. <http://dx.doi.org/10.1590/0104-1169.0196.2613>
17. Monteiro M, Matos AP, Coelho R. Adaptação psicológica de mães cujos filhos apresentam paralisia cerebral: resultados de um estudo. *Revista Portuguesa de Psicossomática*. 2004;6(1):115-30. Available from: <http://www.redalyc.org/html/287/28760115/>
18. Carvalho JTM, Rodrigues NM, Silva LVC, Oliveira DA. Qualidade de vida das mães de crianças e adolescentes com paralisia cerebral. *Fisioter Mov*. 2010;23(3):389-97. Available from: <http://www.scielo.br/pdf/fm/v23n3/a06v23n3>
19. Pernambuco (Estado). Microcefalia e outras alterações do sistema nervoso central. Recife (PE): Secretaria Estadual de Saúde; 2017. (Informe Técnico n. 100).
20. Salge AKM, Castral TC, Sousa MC, Souza RRG, Minamisava R, Souza SMB. Infecção pelo vírus Zika na gestação e microcefalia em recém-nascidos: revisão integrativa de literatura. *Ver Eletrônica Enferm*. 2016;18:e1137. Available from: <http://dx.doi.org/10.5216/ree.v18.39888>
21. Ashwal S, Michelson D, Plawner L, Dobyns W. Practice parameter: evaluation of the child with microcephaly (an evidence-based review). *Neurology*. 2009;73:887-97. Available from: <https://www.aan.com/pressroom/home/getdigitalasset/8479>
22. Moreira RM, Oliveira BG, Cruz DP, Bomfim ESB, Camargo CLC, Sales ZN. Qualidade de vida de cuidadores familiares de pessoas com síndrome de Down. *Rev Pesqui (Univ Fed Estado Rio J, Online)*. 2016;8(3):4826-32. <http://dx.doi.org/10.9789/2175-5361.2016.v8i3.4826-4832>
23. Albuquerque S, Pereira M, Fonseca A, Canavarro MC. Family impact and individual adjustment of parents of children with a diagnosis of congenital anomaly: the influence of the child's determinants. *Arch Clin Psychiatry*. 2012;39(4):136-41. Available from: https://www.scielo.br/scielo.php?script=sci_abstract&pid=S0101-60832012000400004&lng=pt&nrm=iso&tlng=en
24. Carvalho JTM, Rodrigues NM, Silva LVC, Oliveira DA. Qualidade de vida das mães de crianças e adolescentes com paralisia cerebral. *Fisioter Mov*. 2010;23(3):389-97. Available from: <http://www.scielo.br/pdf/fm/v23n3/a06v23n3>
25. Sousa SCB, Pires AAP. Comportamento materno em situação de risco: mães de crianças com paralisia cerebral. *Psicol Saúde Doenças*. 2003;4(1):111-30. Available from: http://www.scielo.mec.pt/scielo.php?script=sci_arttext&pid=S1645-00862003000100008

26. Christofolletti G, Hygashi F, Godoy ALR. Paralisia cerebral: uma análise do comprometimento motor sobre a qualidade de vida. *Fisioter Mov.* 2007;20(1):37-44. Available from: <https://periodicos.pucpr.br/index.php/fisio/article/view/18833/18217>
27. Pereira LM, Kohlsdorf M. Ansiedade, depressão e qualidade de vida de pais no tratamento da paralisia cerebral infantil. Universidade Católica de Brasília. *Interação Psicol.* 2014;18(1):37-46. <http://dx.doi.org/10.5380/psi.v18i1.28823>
28. Bittencourt ZZLC, Hoehne EL. Qualidade de vida de familiares de pessoas surdas atendidas em um centro de reabilitação. *Ciênc Saúde Colet.* 2009;14(4):1235-9. Available from: <https://www.scielosp.org/pdf/csc/2009.v14n4/1235-1239/pt>
29. Eker L, Tüzün EH. An evaluation of quality of life of mothers of children with cerebral palsy. *DisabilRehabil.* 2004;26(23):1354-9. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/15742980>
- Sousa LLA, Braga GS, Nunes AKM, Rocha YD, Pereira AS, Leandro RIS, Maia JA. Análise sobre onível de sobrecarga em cuidadores de crianças com paralisia cerebral e autismo. *Brazilian Journal of Development.* 2022;8(5): 33108-33119. <https://brazilianjournals.com/index.php/BRJD/article/view/473>