Evaluation of family impact in parents of children diagnosed with microcephaly caused by Zika Virus

Avaliação do impacto familiar em pais de crianças diagnosticadas com microcefalia pelo Zika Vírus

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RESUMO

Objetiva-se avaliar o impacto familiar em pais de crianças diagnosticadas com microcefalia pelo Zika vírus. Trata-se de um estudo transversal analítico com abordagem quantitativa, utilizando-se de um questionário sociodemográfico e a escala de impacto familiar (EIF). Foram pesquisados 76 pais com filhos em tratamento de reabilitação e readaptação em um centro de referência de Goiânia/GO. Foram realizadas análises descritivas utilizando-se frequência relativa e absoluta, média e desvio padrão. O teste utilizado para avaliar a existência ou não de diferença estatisticamente significativa ($p \leq 0,05$) foi a análise de variância (ANOVA) Scheffé. O pré-natal foi o período predominante do recebimento do diagnóstico de microcefalia. Foi evidenciado uma dificuldade por parte dos pais em encontrar pessoas de confiança para cuidar do filho, bem como, falta de compreensão de outras pessoas pelo fardo que é cuidar do filho deficiente. Os participantes que apresentaram maior tendência em empreender atividades com amigos, festas e bares, também se mostraram mais propensos a atividades físicas e de lazer. Após o choque inicial do recebimento do diagnóstico, os pais passam reorganizar e adaptar aos desafios, alterando a rotina familiar. É fundamental o envolvimento dos profissionais de saúde, fornecendo suporte e orientação a essas famílias.

Palavra-chave: Infecção pelo Zika vírus; Microcefalia; Saúde da Família.

ABSTRACT

Aimed to evaluate the family impact in parents of children diagnosed with microcephaly by the Zika virus. This is a cross-sectional analytical study with a quantitative approach, using a sociodemographic questionnaire and the Family Impact Scale (FIA). A total of 76 parents with children in rehabilitation and rehabilitation treatment were surveyed at a reference center in Goiânia / GO. Descriptive analyzes were performed using relative and absolute frequency, mean and standard deviation. The test used to evaluate the existence or not of a statistically significant difference ($p \leq 0.05$) was the analysis of variance (ANOVA) Scheffé. Prenatal care was the predominant period for the diagnosis of microcephaly. It was evidenced a difficulty for the parents to find reliable people to take care of the child, as well as lack of understanding of others for the burden of caring for the disabled child. Participants who showed a greater tendency to engage in activities with friends, parties and bars were also more prone to physical and leisure activities. After the initial shock of receiving the diagnosis, the parents reorganize and adapt to the challenges, changing the family routine. The involvement of health professionals is essential, providing support and guidance to these families.

Keywords: Zika Virus infection; Microcephaly; Family health.

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INTRODUCTION

In 2015 Brazil saw an increase of cases of children with microcephaly, which contrasted to a history of the past four years(1). Before the epidemic of Zika Virus in 2015, registers of microcephaly in Brazil were less than 150 cases per year(2). In 2016, scientists of the Center for Disease Control from Atlanta/USA published the causal certificate between microcephaly and other brain damages to Zika Virus(3-4).

The uncontrolled proliferation of the vector *Aedes aegypti* is a fact for Brazilians, which is evident by the constancy of the dengue virus for decades. It largely contributed by the expansion of many suspected cases of Zika, as well as the confirmed ones. The great question about this new disease are the possible consequences for human health, like the growth of microcephaly cases in the country and the alarming number of cases of patients with the Guillain-Barré syndrome(5).

When a family is waiting for a child to be born, many are the expectations and celebrations, as well as anxiety and doubts related to the child's future, involving life and health. These feelings must be intensified when the genitors receive the notification that their baby can be a disabled person, specially nowadays, with the increase of the incidence of Zika virus and, consequently, microcephaly in newborns(6).

There are many fantasies which permeate the genitors' dreams, considering nobody never plans on having a disabled baby(7). The birth of a disabled baby is a unique event in the genitors' lives, once they will then have to deal with the situation of the conceived child instead of the expected and idealized child(8).

The impact of the alterations provoked by the diagnosis must be acknowledged by professionals. Since receiving the diagnosis, there are many changes on the family routine, directing all the attention to the sick child, demanding more time and dedication on this assistance, putting aside other tasks, like caring about other children, husband, house, study and leisure(9).

The family impact is represented by the accumulation of tasks and by the lack of a person who can help taking care of the disabled child by supervisioning this care, in daily activities or financially(10-11).

Diagnosis evaluation of a unique and critical event on the family dynamics is extremely significant and needs many information which solve all questionings, including the impact of this event in the family under the parents' perspective. Thus, this study aimed to evaluate the family impact on parents of children diagnosed with microcephaly caused by Zika virus.

METHODOLOGY

This is a transversal and analytical study with quantitative approach. This research method aims to generate information about the prevalence of the disease exposure and other population features. However, the results inform about the situation at a particular moment, which is very useful in health planning(12).

The research was carried out through questionnaires applied to parents of children diagnosed with microcephaly, during their rehabilitation therapies, medical appointments and exams at the State Center for Rehabilitation and Readjustment DR Henrique Santillo (CRER) in Goiânia/GO.

The CRER is a philanthropic hospital complex which is reference in the Center-West region. It offers services of rehabilitation, medical and surgical clinic at the area of health assistance, and it also encourages teaching and research.

For the sample calculation we used the number of patients attended in the last two months (January and February 2017) which precedes data collection. During this period, between the criteria of inclusion and exclusion, 94 children were attended. With this population we used a confidence level of 95% and margin of error of 5%. The final sample was 76 mothers or fathers of children diagnosed with microcephaly who were undergoing rehabilitation treatment at CRER.

The obtention of consents and data collection occurred among March and June 2017. As inclusion criteria there are: only parents (mother or father) of a child diagnosed with microcephaly; agreement on participating on the research; cognitive ability to answer to the questionnaire; and parents older than 18 years old. The exclusion criteria considered, which mean, sample which was not considered on this research were: refusal on participating the research; minor aged parents; individuals who wanted to exclude their data from the research and parents diagnosed with depression.

We used a psychosocial occupational and health questionnaire which identified data as: sex, age, number of children, marital status, work situation, family monthly income, schooling and housing; and questions related to the family context referring to the moment the news was received and they were aware of the microcephaly.

We used the Family Impact Scale (FIS), which consists on a measure of the impact of the children's disease/disability in the family, considers the effects the children have on the family on the social level, evaluating the overload (global family impact) in a one-dimensional way(13).

In the 1980s, Stein and Jessop developed a clinical study in children which was capable of measuring family impact and their repercussions on the level of the family dynamics, through the consequences caused by a children's chronic disease. Initially, the scale was composed by 33 items, but they were reduced to 24 items due to missing cases, the items referring to the impacto on these children's siblings(13).

The appeal to the confirmatory factor analysis, developed by Albuquerque et al.(14) made it possible to confirm the one-dimensional structure of the FIS, suggesting overload related to care provision to a disabled child is a one-dimensional construct, which integrates the perception of negative effects in the caregiver (individual repercussions, but also on family and social levels)(14).

The family impact scale used at this study was reviewed, resulting in a 15-item scale of Likert type, allowing us to know the degree of conformity and attitude of the interviewees, varying from zero (strongly disagree), one (disagree), two (agree) and three (totally agree). The scores were obtained by the addition of the 15 items, resulting in a variation from 15 (no family impact) to 60 (high family impact). The higher the score, the bigger is the perception of family impact due to the children's health condition(14).

After applying the collection tools, we built a data basis using the software IBM SPSS Statistics 18. Through this software we realized the descriptive analysis of the variables referring to the subject of study, using absolute (n) and relative (%) frequency, average and standard deviation.

The normality of data was confirmed by Shapiro-Wilk tests. Thus, the tests used to evaluate the existence of statistically significant difference ($p \leq 0,05$) between independent samples and multiple variables were the Student's T-Test and the analysis of variance test (ANOVA) Scheffé, respectively.

The research was registered on the Platform Brazil at the Health Ministry under the protocol CAAE: 63647316.6.0000.0037. It was also approved by the Research Ethics Committee of the Pontifical Catholic University of Goiás, under the report number 1.958.307.

RESULTS

Altogether, 76 individuals responded to the present study, corresponding to fathers or mothers of children diagnosed with microcephaly under treatment at CRER. Of the total of individuals, 89.5% were female. The minimum age was 18 years old, the maximum age was 59 and the average age was 30 years old. In relation to the marital status, 50% were married or were in a stable union. About color and ethnicity, there was predominance of brown color, with 63.2%. About schooling, 43.4% finished high school, contrasting to only 3.9% of individuals with a postgraduate degree.

Approximately 96.1% practiced any kind of religion, while 63.2% considered themselves to have very strong faith. About monthly income, 57.9% said they received one to 3 minimum wages, corroborating to 77.6% with family income also equals to 1 to 3 minimum wages; 30.3% said they belonged to this family nucleus, supporting four people with such income. The predominant number of kids per family was 2, with 31.6% of the responses, and 46.1% of the families live in a rented house.

About 68.4% of the interviewees said they have some leisure activity and a total of 85.5% said they have internet access. When asked about the frequency they go to bars, parties or meet friends, 40.8% answered they sometimes do, as well as 31.6% of them answered they "sometimes" practice some kind of physical activity. About the frequency the interviewees have some leisure activity, 32.9% of them answered "frequently".

In relation to the frequency they perform some domestic activity, 60.5% of the individuals answered "very often". Around 63.2% of the interviewees deny to have any health problem, however, only 57.9% informed they go to the doctor sometimes, when they feel sick. About the use of medications to treat a health problem, 63.2% deny to use them. A total of 51.3% considered to have good health conditions. With regard to the moment they received their children's diagnosis with microcephaly, 60.5% said it happened during prenatal. All this data can be seen on Table 1.

From the perspective of the epidemiologic profile of the parents interviewed, we could see a positive correlation which identifies that, the older the interviewee, the higher the income ($r = 0.246$ and $p = 0.032$), the family income ($r = 0.244$ and $p = 0.034$), the amount of people who live in the same residence and are supported with the income ($r = 0.433$ and $p < 0.001$) and also bigger is the amount of children ($r = 0.468$ and $p < 0.001$).

An important data is relative to the use of the monthly income. The research identified that the monthly income is reversely related to some important activities to the family. It means that, the higher the monthly income, the lower the tendency of individuals to attend to bars and friends meetings ($r = - 0.318$ and $p = 0.005$), to practice physical activities ($r = - 0.366$ and $p = 0.001$) and to perform activities related to the family leisure ($r = - 0.518$ and $p < 0.001$).

Those individuals whose tendency was to engage into activities with friends, like parties and bars, presented more inclination towards practicing physical activities ($r = 0.465$ and $p < 0.001$) and performing leisure activities ($r = 0.515$ and $p < 0.001$). Corroborating to this data, it was possible to identify that the interviewees who practiced physical activities tended to have family leisure activities as well ($r = 0.794$ and $p < 0.001$). The correlation data can be seen on Table 2.

From the descriptive analysis of the items of the family impact, we could identify an average score of 36.4 (±6.6) for global family impact. As it is a one-factor scale, some

TABLE 1 – Descriptive analysis of psychosocial, occupational and health variables of 76 interviewees (fathers or mothers) of children with microcephaly attended at a reference hospital. Goiânia, GO, Brazil, 2017

Variables		N	%
Gender	Male	8	10.5
	Female	68	89.5
Marital Status	Single	20	26.3
	Married / Stable Union	38	50.0
	Widow or widower	4	5.3
	Divorced / Separated	14	18.4
Color or Ethnicity	White	21	27.6
	Black	7	9.2
	Brown	48	63.2
Schooling	Elementary School	14	18.4
	High School	33	43.4
	Incomplete College	19	25.0
	College Degree	7	9.2
	Postgraduate degree	3	3.9
Religious?	No	3	3.9
	Yes	73	96.1
Do you consider your faith:	Very Strong	48	63.2
	Strong	25	32.9
	Weak	3	3.9
What is your monthly income?	Lower than 1 minimum wage	32	42.1
	1 to 3 minimum wages	44	57.9
What is the family income?	Lower than 1 minimum wage	13	17.1
	1 to 3 minimum wages	59	77.6
	4 to 8 minimum wages	4	5.3
How many people live with you and are supported by the family income?	Two	2	2.6
	Three	13	17.1
	Four	23	30.3
	Five	17	22.4
	More than five	21	27.6
How many children do you have?	one child	15	19.7
	two children	24	31.6
	three children	17	22.4
	four children	11	14.5
	five children	5	6.6
	six children	4	5.3
About housing	Live in your own house (paid)	8	10.5
	Live in your own house (financed)	16	21.1
	Rented	35	46.1
	Ceded	17	22.4
Do you have any leisure activity?	No	24	31.6
	Yes	52	68.4
Do you use the internet?	No	11	14.5
	Yes	65	85.5
How often do you go to bars, parties or friends meetings?	Very often	1	1.3
	Often	20	26.3
	Sometimes	31	40.8
	Hardly ever	14	18.4
	Never	10	13.2

How often do you practice any physical activity?	Very often	5	6.6
	Often	22	28.9
	Sometimes	24	31.6
	Hardly ever	10	13.2
	Never	15	19.7
How often do you have leisure activities?	Very often	6	7.9
	Often	25	3.9
	Sometimes	17	22.4
	Hardly ever	20	26.3
	Never	8	10.5
How often do you do domestic activities?	Very often	46	60.5
	Often	24	31.6
	Sometimes	4	5.3
	Hardly ever	2	2.6
Do you have any health problem?	No	48	63.2
	Yes	28	36.8
Do you regularly see a the doctor?	Yes, every six months	4	5.3
	Yes, once a year	19	25.0
	Sometimes, when I feel sick	44	57.9
	I never see a doctor	9	11.8
Do you use any medication for treating your health problem?	Yes	28	36.8
	No	48	63.2
How would you describe your health in general?	Great	18	23.7
	Good	39	51.3
	Regular	15	19.7
	Bad	4	5.3
When was your child diagnosed?	During prenatal	46	60.5
	At childbirth before medical release	19	25.0
	Some time after medical release	11	14.5

Source: research data

TABLE 2 – Analysis of Pearson correlation on the 76 interviewees (fathers or mothers) of children with microcephaly attended at a reference hospital. Goiânia, GO, Brazil, 2017.

Variables		1	2	3	4	5	6	7	8	9	10	11
1. Family impact	r	1										
	p											
2. How old are you?	r	-0.164	1									
	p	0.158										
3. Do you consider your faith:	r	0.068	-0.140	1								
	p	0.561	0.229									
4. What is your income?	r	-0.216	**0.246***	-0.139	1							
	p	0.060	**0.032**	0.232								
5. What is the family income?	r	-0.140	**0.244***	-0.118	**0.303****	1						
	p	0.228	**0.034**	0.309	**0.008**							
6. How many people live with you and are supported by the family income?	r	-0.023	**0.433****	-0.166	0.086	0.176	1					
	p	0.845	**0.000**	0.152	0.459	0.129						
7. How many children do you have?	r	-0.125	**0.468****	-0.075	0.099	0.115	**0.857****	1				
	p	0.281	**0.000**	0.522	0.393	0.324	**0.000**					
8. How often do you go to bars, parties or friends meetings?	r	-0.146	-0.062	0.026	**-0.318****	-0.218	-0.076	-0.045	1			
	p	0.207	0.594	0.826	**0.005**	0.059	0.511	0.702				
9. How often do you practice physical activities?	r	-0.009	-0.195	-0.005	**-0.366****	-0.096	-0.185	-0.148	**0.465****	1		
	p	0.941	0.091	0.965	**0.001**	0.408	0.109	0.202	**0.000**			

10. How often do you have leisure activities?	r	0.028	-0.150	-0.012	**-0.518****	-0.202	-0.145	-0.110	**0.515****	**0.794****	1	
	p	0.809	0.196	0.918	**0.000**	0.080	0.213	0.346	**0.000**	**0.000**		
11. How often do you do domestic activities?	r	0.007	-0.175	**0.276***	0.074	-0.140	-0.113	-0.020	-0.128	-0.137	-0.135	1
	p	0.953	0.131	**0.016**	0.523	0.226	0.332	0.864	0.269	0.239	0.243	

**. The correlation is significant at the level 0.01 (2 extremities).
*. The correlation is significant at the level 0.05 (2 extremities).
Source: research data.

special points stand out, taking as a reference the averages of each item of the scale, which varies from one to four. Two items obtained the lowest average scores: item 7, "sometimes I ask myself if my child should be treated specially or as a normal child" (1.8±0.8) and the item 14 "going to the hospital is stressful to me" (2.0±1.0).

On the other hand, the items with highest average scores were: item 4 "it is hard to find someone reliable to take care of our child" (3.3±0.8); item 13 "nobody understands the burden I bear" (2.8±0.9); and the item 8 "I don't think about having other children due to my child's health problem" (2.8±1.0). The FIS data can be seen on Table 3.

However the analysis of the statistical data has not shown significance (p<0.05), some indicators are necessary to be presented in order to characterize the sociodemographic variables in relation to family impacto. Higher scores or family impact were found on the age group from 29 to 38 years old (37.8±6.3), in divorced people (37.4±5.3), on those who informed to have regular health conditions (38.2±6.7) and in families with monthly income lower to a minimum wage (39.2±6.7). This data can be seen on Table 4.

DISCUSSION

This study identified the large majority of inter-

TABLE 3 – Descriptive analysis of the Family Impact Scale of the 76 interviewees (fathers or mothers) of children with microcephaly attended at a reference hospital. Goiânia, GO, Brazil, 2017.

Items of the Family Impact Scale	M	DP
1- Due to my child's problem, we cannot travel outside of our city.	2.09	1.07
2 - People in the neighborhood treat us differently due to our child's health problem.	2.47	1.00
3 - We don't usually want to go out due to our child's health problem.	2.05	0.91
4 - It is hard to find someone reliable to take care of our child.	3.37	0.85
5 - Sometimes we have to change our plans of going out at short notice due to our child's health conditions.	2.70	0.82
6 - We spend less time with family and friends due to our child's health problem.	2.36	0.87
7 - Sometimes I ask myself whether my child should be treated specially or as a normal child.	1.87	0.84
8- I don't think about having other children due to my child's health problem.	2.80	1.02
9 - I don't have much time left for other family members after taking care of my child.	2.41	0.88
10 - Our family renounces some things due to our child's health problem.	2.64	0.89
11 - Fatigue is a problem for me due to my child's health problem.	2.30	0.86
12 - A live one day at a time and don't make plans for the future.	2.05	0.94
13 - Nobody understands the burden I bear.	2.84	0.98
14 - Going to the hospital is stressful to me.	2.00	1.01
15 - Sometimes I feel like I riding a rollercoaster: in crisis when my child gets very sick, and wee, when things are stable.	2.45	0.93
GENERAL FAMILY IMPACT	36.41	6.69

Source: research data.

viewees as mothers, which corroborates with other data, which make evident the mother's role as the main caregiver. In research about the life circumstances of disabled children and their relation to social instability, involving networks for support and healthcare, we obtained similar results, concluding the main caregivers were mothers(15). Under this perspective, in other study, mothers represented the totality of main caregivers on the methodology of taking care of children with chronic neurological disease, carrying several responsibilities and taking care of their children full time(16). In the study of Simões et al.(17), about 68

TABLE 4 – Analysis of variance (ANOVA) of sociodemographic data with Family Impact Scale of the 76 interviewees (fathers or mothers) of children with microcephaly attended at a reference hospital. Goiânia, GO, Brazil, 2017.

Variables	Family Impact			
Age	N	**(A ± SD)**	**P**	
18 to 28 years old	34	36.2 ± 6.7	0.30	0.30
29 to 38 years old	26	37.8 ± 6.3		
over 38 years old	16	36.5 ± 7.0		
Faith				
Very strong	48	36.1 ± 6.6	0.73	
Strong	25	36.4 ± 7.1		
Weak	3	39.3 ± 3.5		
Color				
White	21	34.9 ± 6.3	0.37	
Black	7	38.8 ± 8.9		
Brown	48	36.6 ± 6.4		
Marital Status				
Single	20	36.2 ± 6.7	0.68	
Married / Stable Union	38	36.5 ± 7.1		
Widow / widower	4	32.7 ± 6.8		
Divorced / Separated	14	37.4 ± 5.3		
Family income				
Lower than 1 minimum wage	13	39.2 ± 6.7	0.22	
1 to 3 minimum wages	59	35.7 ± 6.6		
4 to 8 minimum wages	4	37.5 ± 5.0		
Schooling				
Elementary School	14	36.6 ± 7.0	0.97	
High School	33	36.2 ± 7.0		
Incomplete College	19	36.3 ± 7.7		
College degree	7	37.5 ± 5.7		
Postgraduate degree	3	34.3 ± 4.0		
How many children				
One	15	35.3 ± 5.9	0.22	
Two	24	38.7 ± 6.7		
Three	17	34.9 ± 5.0		
Four	11	37.6 ± 8.6		
Five	5	34.6 ± 4.5		
Six	4	31.5 ± 9.2		
How often do you go to bars, parties or friends meetings?				
Very often	1	39.0 ± 0.0	0.79	
Often	20	37.5 ± 6.4		
Sometimes	31	36.6 ± 7.9		
Hardly ever	14	37.0 ± 4.4		
Never	10	35.0 ± 6.2		
How often do you practice physical activities?				

Very often	5	32.6 ± 4.5	
Often	22	37.1 ± 4.7	
Sometimes	24	36.7 ± 8.1	0.48
Hardly ever	10	38.3 ± 9.9	
Never	15	34.8 ± 4.9	
How often do you have leisure activities?			
Very often	6	32.8 ± 5.5	
Often	25	36.8 ± 5.9	
Sometimes	17	37.8 ± 7.5	0.59
Hardly ever	20	35.7 ± 7.7	
Never	8	36.2 ± 4.9	
How often do you do domestic activities?			
Very often	46	36.3 ± 6.6	
Often	24	36.5 ± 7.4	0.99
Sometimes	4	36.5 ± 5.0	
Hardly ever	2	36.0 ± 4.2	
Do you usually go to the doctor?			
Sim, 6/6 meses	4	31.2 ± 9.6	
Sim, 1 vez ao ano	19	37.4 ± 7.1	0.41
Às vezes, só quando passo mal	44	36.5 ± 6.5	
Nunca vou ao médico	9	36.0 ± 4.5	
How would you describe your health in general?			
Great	18	35.1 ± 6.0	
Good	39	36.6 ± 6.2	0.42
Regular	15	38.2 ± 6.7	
Bad	4	33.0 ± 12.6	
When was your child diagnosed?			
During prenatal	46	37.1 ± 6.4	
At childbirth, before medical release	19	36.8 ± 6.8	0.12
Some time after medical release	11	32.5 ± 6.8	

A, average; SD, standard deviation

Source: research data

(85%) of the sample participants were composed by women as caregivers.

In research which aimed to evaluate the impact of a child with microcephaly on mothering, they identified that this process is lived by the mother more sagaciously, exactly because she has generated the baby. It was also possible to verify that the mothers resigned from other social roles, like housewife, wife, professional, mother of other kids, citizen and student. Many of the mothers investigated put those roles in a second plan and started dedicating themselves exclusively to the microcephalus child(18). In the great majority of the families the women stand out as a vital caregiver for the child, once the father already takes responsibility for the material overload demanded by a child with a chronic disease(19).

The data referring to the monthly income of interviewees corresponded to, in most cases, one to three minimum wages. Other studies also show a monthly income in the same parameters in researches with parents of children with diseases which are similar to microcephaly(16-17). The financial situation is pointed by mothers as a difficulty(18).

Children who have some kind of chronic disease will demand more specific cares and many times demand constant visits to hospitals, as well as they may also need recurring hospitalization. Besides the emotional and family distress, there are direct material costs, corroborating to an increase of indigence(19).

In a study with families of children with chronic disease, it was identified that those kids demand more capital for investment, once they need a series of specialized care, which involves financial cost. This study also shows that the spending with children who needed special care due their chronicity is three times higher than the spending on children with perfect health conditions. The child's chronic health condition may demand around 40% of the family's financial resources(20).

According to the great majority of interviewees for this study, the diagnosis of microcephaly was given still during pregnancy. Corroborating to this result, a study which researched parental experience about receiving the diagnosis of microcephaly showed that the perinatal period was the most prevalent period for revealing the diagnosis to the parents(21).

A research which investigated 22 pregnant women who had microcephaly children due to infection with Zika virus identified that 19 of them were informed about the diagnosis in the first trimester of pregnancy(22). Gomes et al.(23) also show gestational period as the moment the parents received the diagnosis.

About the social interactions of the participants on this study, it became evident that the higher their monthly income, the lesser the tendency they presented to go to bars or meeting friends, as well as practicing physical activities or performing activities related to the family leisure.

After a disabled child is born the family tends to abstain from leisure activities. Social deprivation reflects on the parent's tiring routine on managing the demand for taking care of the child, going to therapies and medical appointments, as well as the parent's jobs(20).

The financial aspect plays an essential role on the social life of the family of a microcephalus child. In a circumstance of social fragility, it reaches the family dynamics, forcing better money management, as well as the establishment of priorities for applying this resource, which tends to be scarce(20).

According to the data of this research and taking into consideration the average score obtained for global family impact, the participants who showed higher tendency on engaging in activities with friends, like parties and bars, also showed to be more prone to physical and leisure activities.

A research identified that even with the daily obstacles, the genitors said that they also took advantage of the leisure activities they provided to their kids, showing personal satisfaction. These activities include watching television, massage or even chatting(17). Salvador et al.(19) assume that families who practice physical activities can get stronger and reduce stress.

The study of Neves et al.(24) identified as a strategy for reconfiguration of the family dynamics the creation of connections for social support in the institutional network, as the community, educational and leisure areas, as well as in the religious spaces, creating many health segments aiming to get appropriate treatment.

The main support basis is family, which can be seen as the main social unity in which the individual is inserted and the first entity which helps on the socialization and development of this special human being(19). We can define as social support network as a group of individuals who have connections among each other. This social support includes informative questions or resources provided, causing emotional and physical effects, as well as beneficial behavior. The family reorganizes itself in a way it can help the relative in most of the activities so he or she can dedicate time to take care of the child with chronic disease. It guarantees these parents will become more confident and safer during this journey (23).

Thus, the existence of a precise support network is necessary, providing these families emotional support, several information, as well as moments for sharing experiences about taking care of a disabled child.

Nursing assistance is able to reduce the impact suffered by parents and relatives due to the demand of cares given to a child with microcephaly, contributing to a better functioning of the family dynamics, favoring the child's life and their familiars' lives. Health professionals should promote help through strategies of emotional support, using communication and information as therapy activities, corroborating to the fortification of family bonds(19).

It is important for the professional to establish partnership with the parents, allowing moments of listening and acceptance in order to structure the shared assistance to the child. The team has the duty to enable the family to prevent sequels of microcephaly, elaborating specialized interventions of care, like direct and objective observation of the child inserted in the family dynamics, contributing as an effective source of support to parents, minimizing the obstacles caused by the disease(19).

According to the Pan American Health Organization(25), another fundamental aspect faced by genitors and relatives is discrimination and prejudice from the society. The health professional team is responsible for elaborating intersectoral actions of health and education, delivering information to the community in order to provoke changes of behavior, opinion and perception, allowing favorable social alterations.

Besides all the parents' adversity and tiredness in reorganize themselves and conciliate the new family dynamics to the assistance to the microcephalus child, they still have to deal with overexposure on the media and pejorative commentaries. Through social networks, the media can provide incoherent and uncertain information, which great capacity of tormenting and stigmatizing these families(25).

After receiving the diagnosis that her child has a chronic disease, like microcephaly, the mother tends to look for and accept different forms of support which allow her adaptation during the initial phase. One of the strategies more mentioned on researches is faith in God, through spirituality, which guarantees hope and comfort to overcome the adversities generated by the diagnosis, helping on accepting the disease(18-19-21).

It is important to highlight that three items of the FIS scale presented higher average scores, showing areas of a high familiar impact: it is hard to find someone reliable to take care of our child; nobody understands the burden I bear; I don't think of having other children due to my child's health problem.

According to Beviláqua and Afonso(26), chronic disease, through suffering of the sick person from birth to death, may cause individuals, families and social networks to break usual rules with mutual support and solidarity.

As the main caregiver, the mother tends to centralize for herself domestic activities as well as the assistance to the disabled child. Doing so, she ends up losing part of her personal identity, once the child with chronic disease is always present, and because she cannot count with help of others on taking care of her child(27). Taking care of a child with chronic disease may be a lonely practice, once many commitments rely on the mother, which nullifies, for most of them, the other roles which were previously played as a wife, mother of other children, housewife, student and professional(24).

The practice experienced by parents of kids with microcephaly caused by Zika virus infection has changed their family dynamics and routine. These families experience overload in financial, social and psychological levels, related to taking care of the child. It is necessary to provide different kinds of support during this trajectory, like social, affective and financial support, including the special support of the professionals involved in this process(21). Nursing has an essential role on welcoming and assisting these families, once the nurses are always moving and are able to show something unique in the aid provided, obtaining pleasure on performing their jobs(28).

CONCLUSION

The epidemic of microcephaly caused by Zika virus created a generation of kids who will demand specialized care throughout their lives, impacting the lives of hundreds of families. The current scenario shows lack of scientific material involving this relation. It is known that the impact perpasses family environment, causing unexpected trouble and difficulties for these families, where new routines were implemented, priorities were raised and strategies of facing those problems were developed by the involved.

By realizing this study it was possible to verify the mother as the main caregiver, and that they are young, with an average age of 30 years old. Receiving the news that the child has microcephaly is a critical moment, and most of the participants said it happened during prenatal. This research identified that the interviewees had monthly income of one to three minimum wages.

The difficulty on finding someone reliable to take care of the disabled child, the burden the genitors carry for their children and the desire of not having other children were the factors which presented the highest average scores of family impact. About the social interaction of participants, it became evident that the higher the monthly income, the lesser the tendency they present of going to bars and meeting friends, as well as practicing physical activities or perform activities related to the family leisure.

Nevertheless, participants who presented higher tendency of engaging in activities with friends, parties or bars are also more prone to physical and leisure activities. We can see efficient strategies of facing the situation when questioning parents with the items 7 and 14 of the family impact scale.

It is important to mention some limitations of this research which may imply certain caution when interpreting the results. The extension of conclusions might be restrained by the sample size. In contrast, the participation of the interviewees on a specialized and reference health service shows that these parents have a certain advantage in comparison to parents who do not count to such means.

Thus, we believe it is fundamental to develop studies with larger and more expressive samples, allowing the existence of a control group and specific groups for parents. However, even with these limitations, we believe that this study shows important information and considerations related to the family impact for parents with microcephalus children.

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