Socioeconomic vulnerability and microcephaly related to Zika virus in Brazil

Carla de Barros Reis[1] (Orcid: 0000-0002-6118-213) (carla.reis@ensp.fiocruz.br)
Luciano Pamplona de Góes Cavalcanti[2] (Orcid: 0000-0002-3440-1182) (pamplona.luciano@gmail.com)
Cristina Barroso Hofer[3] (Orcid: 0000-0001-8633-0913) (cbhofer@hucff.ufrj.br)
Claudia Cristina de Aguiar Pereira[1] (Orcid: 0000-0003-1389-9214) (pereirac.claudia@gmail.com)

[1] Fundação Oswaldo Cruz, Escola Nacional de Saúde Pública. Rio de Janeiro-RJ, Brazil.
[2] Universidade Federal do Ceará, Fortaleza-CE, Brazil.
[3] Universidade Federal do Rio de Janeiro. Rio de Janeiro-RJ, Brazil.

Abstract: **Objective:** To carry out a descriptive analysis of direct private household health expenditures and socioeconomic vulnerability associated with the condition of Microcephaly, one of the most evidence manifestations of Congenital Zika Syndrome (CZS). The outbreak of microcephaly and other neurological disorders in children under one year of age was linked to Zika virus infection during the 2015-2016 epidemic in Brazil. **Method:** Ninety-six interviews were carried out in two specialized care centers for children with microcephaly in the cities of Rio de Janeiro and Fortaleza, Brazil. The structured questionnaire covered sociodemographic characteristics, out-of-pocket expenditures associated with the disease, and strategies adopted by families to deal with the financial challenges imposed by the congenital anomaly. **Results:** The households were mostly headed by non-whites and belonged to classes C and D-E. Expenditures on medicines accounted for 78% of medical expenses, while transportation represented 46% of private non-medical expenses. Most households faced debt and reduced domestic consumption, including food, to meet the expenses incurred by the disease. **Conclusion:** Microcephaly appears to reinforce the socioeconomic vulnerability of families, reinforcing the vicious circle characteristic of the health-poverty trap conceptual approach.

➤ **Keywords:** Microcephaly. Congenital Zika syndrome. Out-of-pocket health expenditures. Health-poverty trap.

Received on: 10/20/2022 Revised on: 9/20/2023 Approved on: 12/16/2023

DOI: http://dx.doi.org/10.1590/S0103-7331202434SP113en

Editor: Jane Russo Reviewers: Arlinda Moreno and Marco Aurelio Nascimento

Introduction

Considered a national and international public health emergency in the years 2015-2016, the Zika epidemic had short and long-term implications that deepened poverty and pre-existing inequalities (GÓMEZ *et al*., 2020), in addition to exposing weaknesses in health systems and the challenges to be faced to meet the targets of the Sustainable Development Goals (SDGs).

The Zika virus was identified in 1947 but received little attention until human outbreaks occurred in Micronesia (2007) and French Polynesia (2013) (McNeil, 2016; WHO, 2016). In April 2015, the Brazilian Ministry of Health identified a Zika outbreak in the Northeast region of the country and notified the World Health Organization. Thus, the virus gained global notoriety. In 2016, the outbreak intensified and spread to other countries in the Americas. One of the great challenges arising from the Zika epidemic was the virus's capacity for intrauterine infection, which led to cases of microcephaly, congenital abnormalities, premature births, cognitive and sensory problems, motor disabilities and even the death of fetuses and babies (Caine *et al*., 2018). This set of anomalies was characterized as congenital Zika virus syndrome (ZSC), with microcephaly being one of the most evident manifestations of the disease.

According to the Public Health Emergency Operations Center on Microcephaly of the Ministry of Health, more than ten thousand cases of microcephaly were reported across the country, with 60% of children born in municipalities in the Northeast region (Brasil, 2016). Studies on the prevalence of microcephaly in Brazil suggest that the group most susceptible to the disease is made up of young, black or mixed-race mothers and belonging to families of low socioeconomic status, indicating the potential for increasing social inequities (Butler, 2016; Marinho *et al*., 2016).

Faced with urgent demand, the Brazilian health system faced challenges in ensuring rapid care for children born with microcephaly, issuing guidelines for specialty care and early stimulation. However, in addition to demanding effective responses at government levels, the disease has dramatic repercussions on various spheres of family members' lives. In particular, the socioeconomic consequences at home can be substantial.

Shocks to the health stock, such as their influence on spending on health goods and services, functional capacity and loss of income and productivity, can be a primary risk factor for impoverishment, altering the present and future income generation capacity of individuals and quality of life at home. In response to a certain disease condition, changes occur in the pattern of income and expenditure, and individuals may be led to liquidate household assets and savings or to increase family debt and the level of poverty. Thus, there is damage to the formation of physical, financial and human capital of those involved and the consequent reduction in future consumption possibilities (WHO, 2009).

In this sense, understanding the simultaneity in the relationship between microcephaly and poverty is fundamental for the development and implementation of prevention and treatment strategies for the disease. The generation of evidence regarding the socioeconomic aspects of microcephaly, in different contexts, perspectives and dimensions, is extremely relevant for understanding the varied implications of the disease and improving public policies to combat the syndrome.

Using a descriptive and exploratory approach, this study aims to carry out an analysis of direct private household spending on health and socioeconomic vulnerability associated with the condition of microcephaly, during the outbreak of the disease and other neurological disorders that occurred with the Zika virus epidemic. in Brazil, in years 2015-2016.

Socioeconomic vulnerability is understood here as a condition of material and social fragility of individuals or groups in the face of risks produced by a given economic-social context (Monteiro, 2011). It is a multidimensional concept, shaped by exposure to risks of different natures – be they economic, health, cultural or social – that pose different challenges to confront. In this sense, the term alludes both to the precariousness of material living conditions in the face of some change or permanence of undesirable situations, and to the response capacity that individuals or social groups present in relation to these challenges (Busso, 2001).

Understanding the implications of the disease, considering the perspective of affected families and the financial burden borne by them, reveals the coping strategies adopted by household members and can signal the need to improve public policies aimed at this population.

Methods

The health-poverty trap and the congenital anomaly of microcephaly

Although loss of income and health problems reinforce each other, generating a vicious circle of suffering and material deprivation, most studies in the field of public health focus on the role of socioeconomic elements in determining the health-disease process (Buss; Pellegrini Filho, 2007; Carrapato; Correia; Garcia, 2017; Marmot, 2005).

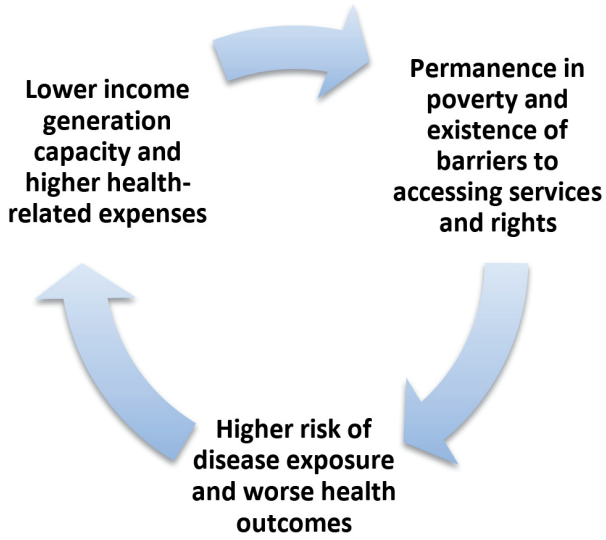
The main channels through which income affects health involve not only meeting the basic needs of a household for the survival of its members, but also expanding the possibilities of choice (Sen, 2000). People with a higher level of income have greater possibilities of purchasing health goods and services; better nutritional and food security conditions; and better housing conditions, with access to drinking water and sanitation. Furthermore, according to Grossman, education increases the efficiency with which individuals invest in their health, given that an increase in the level of information provides greater recognition of the benefits of a good state of health, increases the ability to adequately follow up on any ongoing treatments and facilitates the adoption of healthy lifestyle habits (Grossman, 1972). For all these reasons, individuals in poverty are more likely to suffer negative health shocks (Sala-I-Martin, 2005).

Causality can also occur in the opposite direction, such that health affects income level. According to human capital theory, health would have direct and indirect impacts on income. The direct effects occur through the impact of health conditions on individuals' productivity and ability to offer work. This evidence is perceived both at the microeconomic level, at the level of household spheres, and in terms of aggregate income. Indirect effects refer to the possible positive impacts of health on the other element of the human capital function – education. Healthy children have higher levels of performance and school attendance, with consequences for the intergenerational reproduction of poverty. By influencing the life expectancy of parents and children, health also affects education through a greater return on investment in human capital. Thus, the more years individuals expect to live, the greater their expectations regarding future salaries after discounting the costs of investing in education. The same logic can be established in terms of physical capital accumulation: individuals have greater incentives to create savings, the greater their survival expectations (Santos; Jacinto; Tejada, 2012).

In the household environment, the condition of illness has immediate impacts as it can lead to a reduction in the normal level of productive activity, increase spending on health goods and services, reduce the possibilities of consumption of other goods not related to health – including those related to subsistence – induce the liquidation of assets and debt, and reduce investment in physical, human and social capital (Alam; Mahal, 2014; Engelgau; Karan; Mahal, 2012). At the macroeconomic level, the disease can impact the growth of gross domestic product (GDP), by decreasing productivity in the labor market, affecting tourist activities and commercial transactions, changing the demographic composition, and reducing national savings and investment in training of physical capital (Martelli *et al.*, 2015; UNDP, 2017; WHO, 2009).

Thus, international experience has shown the disease not only as a manifestation, but also as a cause of the condition of poverty (OECD, 2003). As can be seen in Figure 1, this simultaneity relationship means that low levels of income cause poor health, which, in turn, reinforces the inability to generate income, generating a vicious circle called the health-poverty trap.

Figure 1. The health-poverty trap



Under this condition, posed by the Health-Poverty Trap, individuals, households and communities become trapped in a state of low productive capacity, material deprivation and greater risks of contracting diseases (Nyakto; Pelupessy, 2011; Thanh *et al*., 2013; Whitehead; Bird, 2006).

Furthermore, certain health shocks reinforce the condition of chronic poverty, imposing multidimensional deprivation for several years or even transmitting between generations. Five main traps that support chronic poverty can be identified. Insecurity regarding living and housing conditions, with decisions being funneled towards the short term or survival issues; *limited citizenship*, which highlights the lack of effective political representation to ensure that rights and needs are met; *spatial disadvantage*, which traps individuals in remote regions with weak economic integration or marginalized urban spaces with non-existent or low quality public service provision; *social discrimination*, in which relationships are permeated by exploitation, stigmatization and denial of rights; and *poor work opportunities*, characterized by limited chances of generating income and accumulating assets or a high degree of exploitation in activities (CPRC, 2008).

These relationships are still permeated by sociocultural characteristics, with even more significant impacts on the most vulnerable populations, such as the inequality of gender roles in the distribution of domestic work, family care and productive capacity in the labor market.

Evidence suggests that this appears to represent the vicious circle in which families with children affected by microcephaly find themselves in Brazil. While the short-term costs in the first two years of the Zika epidemic correspond to an estimated value of between US$7-18 billion, the long-term costs could reach US$39 billion and are associated with the loss of future income of people who will not be able to join the workforce due to microcephaly and Guillain-Barré syndrome. The impact is disproportionately greater in the poorest regions, especially in the most vulnerable population subgroups, mainly poor and non-white women living in peripheral urban centers. In these locations, households face persistent disparities in access to health and sanitation services, worse insertion in the labor market and less bargaining power and political pressure to guarantee rights and social assistance (UNDP, 2017).

Study design

The cross-sectional study, of a descriptive and exploratory nature, was based on the collection of primary data, through a structured questionnaire. The children included in the study received clinical care at two specialized care points in the cities of Fortaleza and Rio de Janeiro. These locations host a series of services for children with microcephaly from different parts of the respective Federation Units. The first refers to the Institute of Childcare and Pediatrics Martagão Gesteira, at the Federal University of Rio de Janeiro, responsible for caring for a cohort of 26 children diagnosed with the disease. The second collection point refers to the non-governmental organization Instituto Caviver, located in the city of Fortaleza, which serves 120 children diagnosed with microcephaly, through multidisciplinary teams. All patients from both cohorts were recruited to participate in the study.

The questionnaire was administered in July 2017 and January 2018 and was carried out by five postgraduate students who received training for fieldwork. At both points of care, the surveys were carried out in person and immediately after consultation with the pediatrician or a professional from the multidisciplinary team. The instrument was applied to the family member responsible for monitoring the patient during medical care and who lived in the same household as the child. Of a total of 96 interviews, 80 took place in the city of Fortaleza. In the city of Rio de Janeiro, only 16 of the 26 guardians accompanying the children followed by the cohort agreed to participate in the study.

The study was approved by the Research Ethics Committee of the Oswaldo Cruz Foundation (reference number 2,180,892) on July 20, 2017, and followed all ethical research standards in accordance with Brazilian legislation. All participants signed the Free and Informed Consent Form and were informed about the guarantee of reliability and privacy of the information. The respondent was free to refuse to answer any of the questions in the questionnaire, if he preferred. Furthermore, participants were informed that the material would be stored in a safe place and kept by the researchers for at least five years after the questionnaire was administered.

Data collection

The data collection instrument consisted of three blocks of questions and was prepared by the researchers following the example of household surveys carried out by the Brazilian Institute of Geography and Statistics (IBGE).

The first block included questions about the demographic and socioeconomic characteristics of the respondent and household. Regarding information from the respondent and the head of the household, like the questions in the National Household Sample Survey (PNAD/IBGE), variables such as education, sex, color/race, age, marital status, possession of a health insurance, monthly income were included, in addition to the situation and position in the job market. Regarding the characterization of the child affected with microcephaly, information was researched on age, age at diagnosis, color/race and possession of health insurance. As for household conditions, variables on total expenses, monthly household income and members' spending on housing and food were included, which reflect the family's social reproduction condition. The socioeconomic stratum to which the household belongs was also estimated, measured in terms of the Critério Brasil (ABEP, 2018). Developed based on the Family Budget Survey (POF/IBGE), the Critério Brasil development methodology classifies families into six socioeconomic strata based on items of consumer goods and services, water supply condition and street paving, and the level of education of the head of the family.

In the second block of the instrument, also similar to POF/IBGE, information was collected on private household spending on health and payments for health and care expenses associated with the child's illness. The block also covered issues linked to families' coping strategies, such as taking out loans and other financial sacrifices. In the third and final block, we sought to investigate the respondent's health – through self-assessed health questions, diagnosis of anxiety and/or depression and ability to carry out usual activities, in addition to access to social assistance.

Both research fields, Recife and Rio de Janeiro, used the same data collection instrument. The pre-test of the structured questionnaire was carried out with a family member responsible for one of the children with microcephaly in the Rio de Janeiro cohort.

Estimation of private household expenditures associated with the disease

Expenses were collected from the perspective of the household where the child affected by microcephaly resides. Disbursements made by household payments are estimated, covering all private expenses paid directly by consumers to health care providers, that is, health goods and services that are not covered by private health insurance or by another third party payer.

To calculate private expenses associated with the disease, the microcosting technique is used. Common in cost-effectiveness analyses, this technique allows a high degree of detail as it considers each of the components that have contributed to medical care (WHO, 2009). In the first stage, health care procedures were identified based on guidance from experts regarding care needs. The procedures identified as priorities in the care of children diagnosed with microcephaly were physiotherapy, occupational therapy and speech therapy consultations, other medical consultations, medications, laboratory and radiological tests, devices and other consumable items.

In the second stage, the value of care is measured based on the product of the amounts of resource use and the direct measurement of payments and remunerations made (Drummond *et al*., 2005). Thus, medical and non-medical costs are estimated, with the former being directly associated with medical assistance – such as consultations, medicines and devices – and the latter being related to complementary costs to healthcare, such as food, transport, accommodation, and hiring a caregiver for the child (Drummond *et al*., 2005).

As more than 80% of the children in the study were between one and two years old at the time of the study, payments made in the first year of the child's life were collected. Therefore, the estimation of expenses was computed from this temporal perspective.

The fact of using the micro-costing technique allows greater flexibility in choosing the time perspective of analysis, as the measurement of value starts from the quantities and payments made in the period defined in the study. On the other hand, the greater the distance between the response to the survey and the use of the service or purchase of the good, the greater the possibility of memory bias in the responses. It is believed, however, that this problem was minimized by the prior identification, together with specialists, of the main procedures in the care of children diagnosed with microcephaly and an idea about the average frequency of occurrence of each use in the first year of care. Furthermore, memory bias tends to be greater for surveys of families with children over two years of age, which represent only 13.5% of the sample.

Data analyzes took place in 2018. Therefore, the values reported by study participants were adjusted to 2018 prices, by the Broad National Consumer Price Index (IPCA/IBGE). The correction was based on the deflator corresponding to the year of payments reported by the respondent, which varied depending on the age of the child at the time of the survey.

Impoverishment and financial vulnerability

Given the possible costs associated with microcephaly, we estimate the proportion of households whose per capita household income, after deducting direct private expenditure on the disease, is equivalent to or lower than the international extreme poverty and poverty lines adopted by the World Bank. These lines are equivalent to US$1.90 and US$5.50 per day, corresponding to the respective monthly values in reais of R$146.00 and R$420.00, in 2018. In this sense, these values are adopted as references for the minimum income required for the maintenance of subsistence and a minimum material standard of living, so that households with incomes below these respective levels are considered extremely poor and poor (Engelgau; Karan; Mahal, 2012; World Bank, 2018).

As these thresholds are applied uniformly in all regions of the country, without considering inflation and regional differences in the cost of living, a second cutoff methodology is adopted, developed by economist Sonia Rocha, researcher at the Instituto de Estudos do Trabalho e Sociedade (Iets). The approach establishes 25 poverty lines indexed to consumption basket values observed regionally and were corrected to 2018 prices by the IPCA (Rocha, 1997; Rocha, 2015). The extreme poverty and poverty lines are equivalent to R$121.06 and R$315.39; and R$162.38 and R$470.17 for the respective regions of Fortaleza and Rio de Janeiro.

In addition to impoverishment, the proportions of households that have the following coping strategies in the face of the financial vulnerability imposed by the disease are also calculated: i) reduced spending on food; ii) decrease in spending on other consumption items; iii) indebtedness to family, friends, credit institutions and commercial banks; iv) sale of goods or financial assets; and v) withdrawal of savings resources.

All data were coded in a Microsoft Excel spreadsheet and analyzes were performed using Stata 15.0 software.

Analysis and discussion of results

Table 1 shows the characteristics of the households included in the study. Almost 60% of the families interviewed lived in their own or rented property, while 40% paid rent. Most households had water supply from the general network (74%), garbage collection (88.6%) and sanitary sewage through the collection network

or septic tank (91.6%). The heads of families were mostly black or mixed race (71.9%) and half of them did not complete high school. In fact, families afflicted by microcephaly were distributed at the bottom of the social pyramid. These belonged mostly to classes C and D-E, with no representation in class A (richest), which refers to the average household income threshold equivalent to R$ 23,345.11, according to information from POF/IBGE. Only 13.5% of households had a monthly income greater than 3 minimum wages.

These findings are in line with the general characterization of cases of microcephaly at birth carried out by Marinho *et al*. (2016), based on data from the Sistema de Informações sobre Nascidos Vivos (SINASC). The authors found a higher prevalence of the anomaly in babies whose mothers declared themselves black or mixed race, with a lower level of education and who did not have six or more prenatal consultations. A similar profile was found in the study by Gonçalves, Tenório and Ferraz (2018), which sought to characterize the socioeconomic profile of those responsible for children diagnosed with microcephaly related to the Zika virus in the Metropolitan Region of Salvador. Using a structured questionnaire, the authors found a high frequency of black or mixed-race mothers and unemployed fathers, with a monthly income of up to one minimum wage.

In estimates of the socioeconomic impacts of the Zika virus in Latin American and Caribbean countries, the United Nations Development Program also found a disproportionate impact of the disease on poorer and more vulnerable population groups, mainly black women from urban peripheries (UNDP, 2017).

Table 1. Socioeconomic characteristics of the homes of children with microcephaly. Rio de Janeiro and Fortaleza, in 2018 values. (N=96)

	n	%
Condition of the property		
Owned	41	42.7
Rented	39	40.6
Transferred	15	15.7
NS/NR	1	1.0

continue...

	n	%
Water supply		
General network	71	74.0
Well or spring	18	18.8
Other	6	6.2
NS/NR	1	1.0
Sewage system		
Collection network	42	43.7
Cesspool	46	47.9
Other	4	4.2
NS/NR	4	4.2
Garbage collection		
Collected	85	88.6
Burned dor buried	6	6.3
Thrown on vacant land or public place	3	3.1
Other	1	1.0
NS/NR	1	1.0
Color/race of household head		
White	22	22.9
Black	7	7.3
Brown	62	64.6
Indigenous	3	3.1
NS/NR	2	2.1
Education of the household head		
Illiterate/Incomplete primary	10	10.4
Complete primary /Incomplete elementar	21	21.9
Complete elementary/Incomplete high school	17	17.7
Complete high school/Incomplete college	31	32.3
Complete college	10	10.4
NS/NR	7	7.3

continue...

	n	%
Household monthly income		
Up to 1 minimum wage*	31	32.3
1-2 minimum wages	38	39.6
2-3 minimum wages	14	14.6
More than 3 minimum wages	13	13.5
Socioeconomic status ┼		
A	0	0.0
B1	3	3.2
B2	6	6.4
C1	9	9.6
C2	26	27.7
D-E	50	53.2

Source: The authors.

NS/NR: Does not know/Does not answer

* Minimum wage in 2018 = R$954 (present currency).

┼ Total of respondentes Total of respondents for the socioeconomic stratum variable totals 94 because two participants were unable to detail the quantity of all items of goods and services consumed by the household. Detailing these quantities is necessary to calculate the socioeconomic stratum. For more information, see ABEP (2018).

Table 2 shows the average direct private expenses incurred by families due to microcephaly in the first year of the child's life. Total expenses due to the disease represented, on average, approximately 13% of household income. This, in turn, presented an average value of R$23,139.38 annually (R$1,948.58 monthly) and varied between zero and R$240,000.00 annually (R$20,000.00 monthly). In the case of the lower income classes, most medical procedures were carried out through the public health system. In this sense, the non-medical expenses associated with the anomaly were higher than the medical expenses. Households spent, on average, around R$1,506.53 annually on transportation (46%), food (33%) and hiring caregivers (21%); and R$1,201.45 annually in medical expenses, mainly with the purchase of medicines (78%).

These findings corroborate other studies that show that the main item of health expenditure through direct disbursement in the country is expenditure on medicines, especially among the poorest families (Boing *et al*., 2014; Luiza *et al*., 2016). A study showed that for the poorest 10% of the Brazilian population, medicines represented more than 80% of health expenses, highlighting flaws in the policy of free medicine distribution by the SUS (Campino, 2011). The high proportions of direct non-medical expenditure on transport and food, evidenced in this study, may also reflect problems in the health care network at the municipal level, which is responsible for transporting children to the respective health services.

Table 2. Average household private expenditure due to microcephaly and proportion of private expenditure in relation to household income - Rio de Janeiro and Fortaleza, values at 2018 prices. (N=96)

Private Expenditure	R$
Doctors	1,201.45
Consultations	194.48
Medicine	932.82
Exams	72.07
Other	2.08
Non-medical	1,506.53
Transportation	689.52
Feeding	498.26
Caregiver	318.75
Total	2,707.98
% Total/Family income	12.75

Source: The authors.

Table 3 shows that the strategy most used by households to face the socioeconomic vulnerability imposed by microcephaly was debt. Of the 96 households in the study, only one participant declared not knowing the information and 67 were in debt due to the disease, representing 69.8% of the responses.

Regarding other coping strategies, respondents from all 96 households declared that they knew the information. After becoming indebted, the most

frequent alternative found by families to deal with the burden of the disease was to reduce family consumption. While 62.5% of households had to reduce total consumption, 22% sold goods and assets and 13.5% withdrew resources from savings. Almost 40% of households faced a decrease in food consumption, revealing the vulnerability of affected households. These results reveal a deepening of the economic deprivation to which households are exposed when faced with a health shock of the severity of microcephaly.

Table 3. Percentage of households that used coping strategies in the face of socioeconomic vulnerability imposed by microcephaly, according to type of strategy (%) – Rio de Janeiro and Fortaleza, 2018. (N=96)

	n	%
Debt	67	69,8
Reduced consumption	60	62,5
Sale of goods and assets	21	21,9
Savings reduction	13	13,5
Redução de consumo de alimentos	37	38,5

Source: The authors.

Note: Each household can adopt more than one coping strategy.

Considering per capita household income, more than half of the families were located below the poverty line, reaching 60.4% when using the World Bank methodology. Using the same methodology, 4.2% were below the extreme poverty line. After deducting private health expenditures due to microcephaly from per capita household income, these proportions rise to 65.6% and 8.3%, respectively. Using regionalized poverty and extreme poverty lines, the percentage of families considered poor jumps from 48.9% to 52.1%, while the percentage of extremely poor families increases from 3.1% to 4.2% (Table 4). These results highlight the difficult socioeconomic conditions of families affected by microcephaly and how the disease exerts additional pressure on households to remain in poverty.

Table 4. Proportion of poor and extremely poor households, with and without deducting private expenditure on microcephaly from per capita household income (%) – Rio de Janeiro and Fortaleza, 2018. (N=96)

Poverty line	Without deduction	With deduction
Extreme Poverty – World Bank	4.2	8.3
Extreme Poverty - Regional	3.1	4.2
Poverty – World Bank	60.4	65.6
Poverty - Regional	48.9	52.1

Source: The authors.

It is clear, therefore, that microcephaly was an important shock to the economic situation of families, by draining resources to be allocated to other types of goods and services within the household. This situation becomes even more worrying in a middle-income country like Brazil, where high proportions of direct private spending (out-of-pocket) predominate in relation to total health spending. Direct payments represent the most iniquitous health financing mechanism, as it depends exclusively on individuals' ability to pay, without any risk-sharing instruments. Even with the presence of a public system with assumptions of universality, equity and completeness, Brazil has a percentage of private spending corresponding to 50% of the sector's total spending. Of total private spending, around half refers to direct disbursements and the other half goes to paying for health plans (Levi; Mendes, 2015). Furthermore, there has been a tendency towards an increase in catastrophic health expenditure in Brazil in recent decades, especially in poorer households and with less educated heads of families (Boing *et al.*, 2014). For all these reasons, the results presented here indicate the possibility of deepening the situation of poverty and inequity faced by families affected by the disease.

Conclusion

This study aimed to analyze direct private household spending on health and the socioeconomic difficulties faced by families with children affected by microcephaly related to the Zika virus during the 2015-2016 outbreak. Using a descriptive and exploratory approach, based on a structured questionnaire applied in two specialized care centers for children with microcephaly, the study

investigates the implications of the disease on the socioeconomic vulnerability of affected families and the coping strategies adopted by household members in the face of the challenges posed by congenital anomaly.

The results showed that the families affected by the disease are mostly headed by black or mixed-race people and belong to classes C and D-E. Among the medical expenses, those relating to the purchase of medicines stand out, while among the non-medical expenses, the most notable are the costs associated with traveling the child and companion from home to the care center. Most families faced debt and reduced domestic consumption, including food, in order to meet the expenses incurred by the disease. In fact, the condition of microcephaly related to the Zika virus appears to put pressure on the financial burden of households, exacerbating the condition of socioeconomic vulnerability and reinforcing the vicious circle of poverty, characteristic of the health-poverty trap conceptual approach. In this sense, the condition of illness seems to represent, simultaneously, a manifestation and a cause of poverty and multidimensional deprivation.

Obviously, the results found here are not generalizable to the entire population of households affected by microcephaly, as the study is based on a convenience sample and is restricted to just two locations in the country. Furthermore, it was not possible to include, in the analysis, affected families who lived in the municipalities of Rio de Janeiro and Fortaleza, but who accessed health services outside the service points analyzed. However, the findings provide greater detail on the realities analyzed and how families have organized themselves, at least from a financial point of view, to deal with the challenges posed by the disease.

Another limitation of the study is the absence of control groups, to compare the expenses associated with children with microcephaly with those related to children without the manifestation of the congenital anomaly, but who were born to mothers infected by the Zika virus. The use of a convenience sample did not allow us to reach groups with different health outcomes. In this sense, this study only addresses the description of private household spending on health and the socioeconomic vulnerability associated with the disease, instead of measuring the economic impact of microcephaly on families using a baseline scenario.

Another important limitation of this work is the use of cross-sectional data, in which information is recorded at a single moment in time. In addition to making it possible to capture changes in the socioeconomic level of families and the pattern

of household expenditures over time, a longitudinal study design would minimize the occurrence of memory errors, since monitoring could increase the accuracy of information on direct health disbursements.

A research agenda should include follow-up and in-depth interviews, both with family members and health professionals who are involved in the care of these children, in order to investigate, in more detail, issues linked to impacts indirect factors relating to supply capacity and productivity in the labor market, gender inequalities, narrowing in care and health and social assistance services, and psychological impacts and the quality of life of family members.[1]

Financial support

European Union's Horizon 2020 Research and Innovation Programme under ZIKAlliance (Grant Agreement 734548). Fundação Carlos Chagas Filho de Amparo à Pesquisa do Estado do Rio de Janeiro – Faperj (Grant Number E-26/203.210/2016). Fundação Cearense de Apoio ao Desenvolvimento Científico e Tecnológico – Funcap (Grant Number 3968228/2017 – Convênio 837577/2016).

References

ALAM, K.; MAHAL, A. Economic impacts of health shocks on households in low and middle income countries: a review of the literature. *Globalization and Health*, v. 10, n. 21, 2014.

ASSOCIAÇÃO BRASILEIRA DAS EMPRESAS DE PESQUISA. *Critério de Classificação Econômica Brasil*. São Paulo: ABEP, 2018.

BOING, A. C.; BERTOLDI, A. D.; BARROS, A. J. D.; *et al*. Desigualdade socioeconômica nos gastos catastróficos em saúde no Brasil. *Rev. Saúde Pública*, v. 48, n. 4, p. 632- 641, 2014.

BRASIL. Ministério da Saúde. Sala de Apoio à Gestão Estratégica. Situação de saúde. Microcefalia e Zika. Boletim Microcefalia. *Informe Epidemiológico* nº 57/2016. Ministério da Saúde: Brasília, 2016. Available at: http://combateaedes.saude.gov.br/images/pdf/Informe-Epidemiologico-n57-SE52_2016. Access on: 9 Aug. 2020.

BUSS, P. M.; PELLEGRINI FILHO, A. A saúde e seus determinantes sociais. *PHYSIS*: *Rev. Saúde Coletiva*, Rio de Janeiro, v. 17, n. 1, p. 77-93, 2007.

BUSSO, G. *Vulnerabilidad social*: nociones e implicancias de políticas para Latinoamérica a inicios del siglo XXI. Seminario Internacional: las diferentes expresiones de la vulnerabilidad social en América Latina y el Caribe. Santiago de Chile: CELADE, 2001.

BUTLER, D. Brazil asks whether Zika acts alone to cause birth defects. *Nature*, v. 535, n. 7613, p. 475-476, 2016.

CAINE, E. A.; JAGGER, B. W.; DIAMOND, M. S. Animal models of Zika virus infection during pregnancy. *Viruses*, v. 10, n. 11, p. 598, 2018.

CAMPINO, A. Gastos catastróficos, iniquidade e proposta de reformulação do sistema de saúde. In: BACHA, E.; SCHWARTMAN, S., Eds. *Brasil: A nova agenda social.* LCT: Rio de Janeiro, p.104-8, 2011.

CARRAPATO, P.; CORREIA, P.; GARCIA, B. Determinante da saúde no Brasil: a procura da equidade na saúde. *Saúde Soc*. São Paulo, v. 26, n. 3, p. 676-689, 2017. DOI 10.1590/S0104-12902017170304

CHRONIC POVERTY RESEARCH CENTRE. *The Chronic Poverty Report 2008-09*. Escaping Poverty Traps. Brooks World Poverty Institute. School of Environment and Development. The University of Manchester, UK, 2008.

DRUMMOND, M. E.; SCULPHER, M. J.; TORRANCE, G. W. *et al. Methods for the economic evaluation of health care programmes.* Oxford University Press: Oxford, UK, 2005.

ENGELGAU, M. M.; KARAN, A.; MAHAL, A. The Economic impact of Non-communicable Diseases on households in India. *Globalization and Health*, v. 8, n. 9, 2012.

GÓMEZ, E. J.; PEREZ, F. A.; VENTURA, D. What explains the lacklustre response to Zika in Brazil? Exploring institutional, economic and health system context. *BMJ Glob Health*, v. 3, n. 5, p. e000862, 2018. doi: 10.1136/bmjgh-2018-000862.

GONÇALVES, A. E.; TENÓRIO, S. D. B.; FERRAZ, P. C. S. Aspectos socioeconômicos dos genitores de crianças com microcefalia relacionada ao Zika Vírus. *Rev Pesq Fisio*., v. 8, n. 2, p. 155-166, 2018. doi: 10.17267/2238-2704rpf.v8i2.1865

GROSSMAN, M. On the Concept of Health Capital and the Demand for Health. *Journal of Political Economy*, n. 80, p. 223-255, 1972.

IPEADATA. *Indicadores sociais*. Available at: http://www.ipeadata.gov.br. Access on: 4 Oct. 2020.

LEVI, M. L.; MENDES, A. Gasto total com saúde no Brasil: a importância e o esforço de medi-lo. *Domingueira da Saúde*, n. 8, 2015.

LUIZA, V.; TAVARES, N.; OLIVEIRA, M. *et al*. Gasto catastrófico com medicamento no Brasil. *Revista de Saúde Pública*. v.*50*, supl. 2, 2016. DOI:10.1590/S1518-8787.2016050006172

MARINHO, F.; ARAÚJO, V. E. M.; PORTO, D. L. *et al*. Microcefalia no Brasil: prevalência e caracterização dos casos a partir do Sistema de Informações sobre Nascidos Vivos (Sinasc), 2000-2015. *Epidemiol. Serv. Saude*, v. 25, n. 4, p. 701-712, 2016.

MARMOT, M. Social determinants of health inequalities. *Lancet*, v. 365, p. 1099-104, 2005.

MARTELLI, C. M. T. *et al*. Economic Impact of Dengue: Multicenter Study across Four Brazilian Regions. *PLoS Negl Trop Dis.,* v. 9, n. 9, p. e0004042, 2015. doi:10.1371/journal.pntd.0004042

MCNEIL, D. G., JR. *Zika*: The emerging epidemic. New York: Norton, 2016.

MONTEIRO, S. R. R. P. O marco conceitual da vulnerabilidade social. *Sociedade em Debate*. Pelotas, v. 17, n. 2, p. 29-40, 2011.

NYAKATO, V. N.; PELUPESSY, W. Not by money alone: the health poverty trap in rural Uganda. In: MARYSSE, S.; REYNTJENS, F.; VANDEGINSTE, S. *L'Afrique des Grands Lacs:* Annuaire 2010-2011, 2011. Available at: https://medialibrary.uantwerpen.be/oldcontent/container2143/files/Publications/Annuaire/2010-2011/16-Nyakato-Pelupessy.pdf. Access on: 5 Oct. 2020.

ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT. DAC Guidelines and Reference Series. *Poverty and Health*. OECD: Paris, 2003.

PEREIRA, C. C. A. *et al*. Out-of-pocket expenditures associated with congenital zika syndrome in Brazil: an analysis of household health spending. *Jornal Brasileiro de Economia da Saúde*. Rio de Janeiro, v. 14, n. 2, p. 112-2, 2022. DOI: 10.21115/JBES.v14.n2.p112-120

ROCHA, S. Do consumo observado à linha de pobreza. *Pesquisa e Planejamento Econômico*, Rio de Janeiro, v. 7, n. 2, p. 313-352, 1997.

ROCHA, S. *Indicadores de pobreza, segundo unidades de federação, regiões e estratos de residência* - 2014. Rio de Janeiro: Iets, 2015. Available at: <http://iets.org.br/spip.php?article406>. Access on: 11 June 2019.

SALA-I-MARTIN, X. Health and Economic Growth Findings and policy implications. In: LÓPEZ-CASANOVA, G.; RIVERA, B.; CURRAIS, L. (eds.). *Health and Economic growth:* findings and policy implications. Cambridge: MIT Press Direct, 2005. https://doi.org/10.7551/mitpress/3451.001.0001

SANTOS, A. M. A.; JACINTO, P. A.; TEJADA, C. A. O. Causalidade entre Renda e Saúde: Uma Análise Através da Abordagem de Dados em Painel com os Estados do Brasil. *Est. Econ*. São Paulo, v. 42, n. 2, p. 229-261, 2012.

SEN, A. *Desenvolvimento como liberdade*. São Paulo: Companhia das Letras, 2000.

THANH, N. X. *et al*. Fetal Alcohol Spectrum Disorder: Poverty Trap? *Popul Ther Clin Pharmacol,* v. 20, n. 1, p. e63-e66; 2013.

THE UNITED NATIONS DEVELOPMENT PROGRAMME. In partnership with the International Federation of Red Cross and Red Crescent Societies - IFRC. *A Socio-Economic Impact Assessment of the Zika Virus in Latin America and the Caribbean*: with a focus on Brazil, Colombia and Suriname. New York: UNDP, 2017.

WHITEHEAD, M.; BIRD, P. Breaking the poor health-poverty link in the 21st century: do health systems help or hinder? *Annals of Tropical Medicine & Parasitology*, v. 100, n. 5-6, p. 289-99, 2006.

WORLD BANK. *International Bank for Reconstruction and Development*. 2018. DOI: 10.1596/978-1-4648-1330-6.

WORLD HEALTH ORGANIZATION. 2016. *Zika situation report*. Available at: https://www.who.int/emergencies/zika-virus/situation-report/15-september-2016/en/. Geneva: WHO, 2016.

WORLD HEALTH ORGANIZATION. Department of Health Systems Financing. Health Systems and Services. *WHO Guide to Identifying the Economic Consequences of Diseases and Injury*. Geneva: WHO, 2009.

WORLD HEALTH ORGANIZATION. *WHO guide to identifying the economic consequences of disease and injury*. Geneva: WHO Press, 2009.

Nota

[1] C. de B. Reis and C. C. de A. Pereira: conception of the study, writing of the manuscript in all its stages, carrying out statistical analyzes and approval of the final version of the article. L. P. de Cavalcanti and C. Hoffman: conception of the study, writing and approval of the article in its final version.

Resumo

Vulnerabilidade socioeconômica e microcefalia relacionada ao Zika vírus no Brasil

Objetivo: Realizar uma análise descritiva dos gastos privados diretos domiciliares em saúde e da vulnerabilidade socioeconômica associados à condição de microcefalia, uma das manifestações mais evidentes da síndrome congênita do Zika vírus (SCZ). O surto de microcefalia e outros distúrbios neurológicos em crianças menores de um ano de idade foi associado à infecção pelo vírus Zika, durante a epidemia ocorrida no período de 2015-2016 no Brasil. **Método:** Noventa e seis entrevistas foram realizadas em dois centros especializados de atendimento às crianças acometidas por microcefalia nas cidades do Rio de Janeiro e Fortaleza. O questionário estruturado abrangeu características sociodemográficas, gastos com desembolso direto associados com a doença e estratégias adotadas pelas famílias para lidarem com os desafios financeiros impostos pela anomalia congênita. **Resultados:** Os domicílios eram majoritariamente chefiados por não-brancos e pertenciam às classes C e D-E. Os gastos com medicamentos contabilizaram 78% dos gastos médicos, enquanto as despesas com transporte representaram 46% do gasto privado não-médico. A maioria dos domicílios enfrentaram endividamento e redução do consumo doméstico, inclusive de alimentos, a fim de fazer face às despesas incorridas pela doença. **Conclusão:** A microcefalia parece reforçar a vulnerabilidade socioeconômica das famílias, reforçando o círculo vicioso característico da abordagem conceitual da armadilha saúde-pobreza.

➤ **Palavras-chave:** Microcefalia. Síndrome congênita do Zika vírus. Desembolso direto com saúde. Armadilha saúde-pobreza.