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Alessandra Alves de Vasconcelos[1]
Luciana Dadalto[1]
Marcelo Sarsur[1]

ENFORCEMENT OF PUBLIC HEALTH POLICIES PROTECTING CHILDREN WITH CONGENITAL ZIKA SYNDROME AND THE IMPACT ON HEATH JUDICIALIZATION

Efetivação das políticas públicas em saúde protetivas às crianças com Síndrome Congênita do Zika e o impacto na judicialização da saúde

[1]Centro Universitário Newton Paiva. Belo Horizonte/MG, Brasil.

Correspondence: Alessandra Alves de Vasconcelos. *E-mail*: alessandravasconcelos.adv@hotmail.com

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ABSTRACT

The Congenital Zika Syndrome has led to the emergence in Brazil of a universe of children who require medications, medical exams, specialized consultations, besides a rigorous monitoring of their growth and neuropsychomotor development. However, not all of them are able to receive adequate treatment and end up seeking the Judiciary to have their rights enforced. In this context, this article aimed to present the main demands that come to the Judiciary from families with children with this syndrome, as well as to evaluate the scope of health policies instituted to ensure the comprehensive care and social protection of these children and their families. It was found that although the right to health is guaranteed constitutionally and generates to the Public Power, in all its spheres, the duty to provide medical and pharmaceutical care with equity and universality, the allocation of resources and the health care provided to these children were shown to be insufficient and precarious, thus generating a transfer of powers from the Executive to the Judiciary, which becomes the last hope of these families.

Keywords

Right to Health; Equity; Public Policies; Congenital Zika Syndrome.

RESUMO

A síndrome congênita do zika fez surgir no Brasil um universo de crianças que necessitam de medicamentos, exames médicos e consultas especializadas, além de uma vigilância rigorosa de seu crescimento e desenvolvimento neuropsicomotor (DNPM). No entanto, nem todas conseguem receber o tratamento adequado e acabam buscando o Poder Judiciário para ter seus direitos efetivados. Nesse contexto, o presente artigo objetivou apresentar as principais demandas que chegam ao Poder Judiciário por parte das famílias que têm filhos com essa síndrome, bem como avaliar o alcance das políticas de saúde instituídas para garantir a integralidade da atenção e a proteção social dessas crianças e suas famílias. Verificou-se que, apesar de o direito à saúde ser assegurado constitucionalmente e imputar ao poder público, em todas as suas esferas, o dever de fornecer assistência médica e farmacêutica com equidade e universalidade, a alocação de recursos e a atenção à saúde dispensadas a essas crianças demonstraram-se insuficientes e precárias, gerando assim, uma transferência de atribuições do Poder Executivo para o Poder Judiciário, que se torna a última esperança das famílias.

Palavras-Chave

Direito à Saúde; Equidade; Políticas Públicas; Síndrome Congênita do Zika.

Introduction

With the Federal Constitution of 1988 (CF/88), the concept of health was expanded to a model compatible with international human rights policy, in which health is conceived as a right for all and the duty of the State to be guaranteed "through social and economic policies aimed at reducing the risk of disease and services for its promotion, protection and recovery[1]".

The Brazilian National Health System (SUS) was created to meet the constitutional objectives and is regulated by Law no. 8.080/1990, which, in addition to recognizing determining and conditioning factors for the physical, mental and social well-being of individuals[2], has as principles and guidelines the universality of access to health services at all levels, comprehensive care, the preservation of people's autonomy in the defense of their physical and moral integrity, equal assistance, the right to information, community participation and the decentralization of actions and services with an emphasis on municipalities[3].

With regard to the "right to health", a restrictive and distorted interpretation as an individual right is often allowed, assisting each one to demand for themselves the unconditional mobilization of the human and technical means necessary to restore their health. Equity can also refer to different aspects, mainly equity in health care and equity in access to them. It is important to add that this recommended equity in access refers only to primary care, those that are considered determinants to preserve or restore health[4]. However, assistance does not always reach the population at an opportune time and, in the silence of the public authorities or inefficiency in fulfilling what is determined, the Judiciary is demanded in search of guaranteeing assistance to those who need it and are unable to obtain it from ordinary means.

The research report on the judicialization of health commissioned by the National Council of Justice (CNJ) and the Judiciary highlights the growth of approximately 130% in the lower court demands between 2008 and 2017. The research identified 498,715 lower court cases, distributed among 17 state courts, and 277,411 second instance cases, distributed between 15 state courts, between 2008 and 2017.

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[1]BRASIL. *Constituição Federal da República Brasileira de 1988*. Available at: http://www.planalto.gov.br/ccivil_03/constituicao/constituicaocompilado.htm. Accessed on: 26 Aug. 2020.

[2]BRASIL. *Lei n. 8.080, de 19 de setembro de 1990*. Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências. 1990b. Available at: http://www.lei.adv.br/8080- 90.htm. Accessed on: 23 Jul. 2017.

[3]VENTURA. M. *Direitos reprodutivos no Brasil*. 3. ed. São Paulo: Câmara Brasileira do Livro, 2009.

[4]NEVES, Maria do Céu Patrão. Alocação de recursos em saúde: considerações éticas. *Bioética*, v.7, n. 2, p. 155-163, 1999. Available at: https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/download/307/446.

In the second instance, there was a jump from 2,969 cases in 2008 to more than 20 thousand in 2017[5].

Despite the work of the Ministry of Health and international organizations in providing scientific, technological and financial support to promote access for children with congenital Zika syndrome to assistance, care and health recovery established by law, the objective of this work was to verify whether the measures necessary for the effectiveness of assistance are actually being achieved with regard to the monitoring of these children, encompassing consultations, treatments, medications and relevant supplies.

When epidemics like the one in question arise, there is always a need for a reorganization of social protection and health systems to cope with meeting the new demand for care with the appropriate specificities.

For the proposal, firstly, a retrospective of the emergence of the Zika virus in the world and of how it entered Brazil occurred, going from a minor disease with a low need for hospitalization to a change in the pattern of microcephaly occurrence in the country, affecting mainly babies of northeastern women who live in a situation of economic and social fragility. Throughout the article, conceptual definitions of equity are discussed that reinforce its resolution based on judicialization.

In view of the above, the public policies recommended by the organizations involved are questioned in order to guarantee comprehensive care, access to health care services and social protection for these children and their families, and what has been the role of the Judiciary for the comprehensiveness of such actions in the lives of these families and children.

Method

This article deals with a qualitative study of bibliographic review carried out after a survey of specialized literature. For the identification of the sources, the databases *Google Scholar* and *Scientific Electronic Library Online* (SciELO) were used. Initially, the search was made by crossing the keywords "Zika", "microcephaly" and "congenital Zika syndrome", with a return of more than 78 possible references in total, imposing a time limit for articles published from 2015 to 2019.

Legislation on the topic and news published in the media were also used, as well as judged on the theme given by the Court of Justice of Minas Gerais (TJMG).

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[5]CONSELHO NACIONAL DE JUSTICA – CNJ. Relatório Analítico Propositivo. Justiça Pesquisa. *Judicialização da Saúde no Brasil*: perfil das demandas, causas e propostas de solução. INSPER.2019. Available at: http://cnsaude.org.br/wpcontent/uploads/2019/07/JUDICIALIZAC%CC%A7A%CC%83O-DA-SAU%CC%81DE-NO-BRASIL.pdf. Accessed on: 10 Jul. 2019.

The inclusion criteria for the jurisprudential research were: judged from 2015 to 2019 and children with microcephaly, excluding other causes when mentioned. Regarding those judged, 25 judgments were found with the word "microcephaly", but no results were found for the words "microcephaly" and "Zika" together or for the expression "congenital Zika syndrome".

Of the 25 judged, only five met the inclusion criteria. The other 20 had other causes for the occurrence of microcephaly (for example, involvement in adults), were redundant or were outside the cutoff date.

For data analysis, thematic analysis was used, which, according to Bardin[6], is one of the forms that are best suited to qualitative investigations. As the author proposes, the application of this technique consists of three stages: (i) pre-analysis; (ii) exploration of the material; (iii) treatment of results and interpretation.

The emerging themes preferably covered three categories, which are discussed throughout the article, namely: difficulties experienced by families in caring for children; judicialization for the acquisition of medications, treatments and supplies; and scope of assistance recommended by the Ministry of Health for children with congenital Zika syndrome.

I. Emergence of the virus in Brazil and its repercussions

Zika is a virus of the flavivirus genus transmitted by mosquitoes of the genus *Aedes*, mainly the *Aedes aegypti*. It was first identified in monkeys on the African continent, more specifically in Uganda, in 1947, during a monitoring of yellow fever - its transmitter is the same as for diseases such as yellow fever and *chikungunya*. In 1952, it was identified in humans in the Republic of Uganda and the United Republic of Tanzania.

The first major outbreak of the disease caused by Zika infection was reported in 2007 on the island of Yap (Federated States of Micronesia). In July 2015, Brazil reported an association between Zika virus infection and Guillain-Barré syndrome (autoimmune neurological disease) and, in October of the same year, between Zika infection and microcephaly[7].

Until 2015, knowledge about Zika virus infection was that it affected all age groups and both sexes, being an acute febrile illness, self-limited in most cases and with low need for hospitalization. However, from the second half of 2015, infection by the Zika virus began to take on national importance, when clinicians from some

[6]BARDIN, Laurence. *Análise de conteúdo*. Lisboa: Edições 70, 2010.
[7]WORLD HEALTH ORGANIZATION - WHO. Zika: the origin and spread of a mosquito-borne virus. *Bulletin of the World Health Organization*, n. 94, p. 675-686, 2016. Available at: http://www.who.int/bulletin/volumes/94/9/16-171082.pdf. Accessed on: 12 Aug. 2017.

states in the Northeast of Brazil, mainly Paraíba, Pernambuco and Ceará, start to notice and report the increase in microcephaly in newborns - births to mothers who had been infected during pregnancy[8].

On November 11, 2015, the Ministry of Health declared a Public Health Emergency of National Importance (ESPIN) due to changes in the pattern of occurrence of microcephaly in Brazil. Although the increase in cases was registered in Pernambuco, the official statement covered the entire country. By recognizing ESPIN, the Ministry ensured greater speed in investigating registered cases - this mechanism is provided for by law[9], for emergency cases in public health that demand the urgent use of prevention measures, control and containment of risks, damages and injuries public health.

After detecting the increase in cases of congenital defects (CD) possibly related to the Zika virus, clinical, epidemiological and experimental studies started as early as 2015 sought to investigate this causal association, with the contribution of geneticists and other specialists involved. These studies have reached the etiological evidence for what the literature has established as congenital Zika syndrome (CZS), proving the teratogenicity (ability to cause birth defects) of the Zika virus[10].

The congenital Zika syndrome or Zika virus congenital syndrome affects exclusively fetuses and babies infected with the Zika virus before birth and has the following characteristics: severe microcephaly; reduced brain tissue with specific pattern of brain damage; damage to the back of the eye, including a macular scar and retinal spot with focal pigmentation; congenital contractures, such as clubfoot or arthrogryposis and hypertonia, limiting body movements soon after birth. Other anomalies include cerebral atrophy and asymmetry, abnormal formation or absence of brain structures, hydrocephalus and neuronal migration disorders. In relation to neurological abnormalities, there is the occurrence of hyperreflexia, irritability, tremors, seizures, brainstem dysfunction[11] and dysphagia. Abnormalities of the

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[8]WORLD HEALTH ORGANIZATION - WHO. Zika: the origin and spread of a mosquito-borne virus. *Bulletin of the World Health Organization*, cit.

[9]BRASIL. *Decreto n. 7.616, de 17 de novembro de 2011*. Dispõe sobre a declaração de Emergência em Saúde Pública de Importância Nacional - ESPIN e institui a Força Nacional do Sistema Único de Saúde - FN-SUS. Available at: http://www.planalto.gov.br/ccivil_03/_Ato2011-2014/2011/Decreto/D7616.htm#:~:text=Disp%C3%B5e%20sobre%20a%20declara%C3%A7%C3%A3o%20de,de%20Sa%C3%BAde%20%2D%20FN%2DSUS. Accessed on: 08 Jul. 2017.

[10]FEITOSA Ian Mikardo Lima; SCHULER-FACCINI, Lavinia; SANSEVERINO, Maria Teresa Vieira. Aspectos importantes da Síndrome da Zika Congênita para o pediatra e o neonatologista. *Bol Cient Pediatr*., v. 5, n. 3, p. 75-80, 2016. Available at: https://www.sprs.com.br/sprs2013/bancoimg/170118173954bcped_05_03_a02.pdf.

[11]MINISTÉRIO DA SAÚDE – MS. Secretaria de Atenção à Saúde. *Diretrizes de estimulação precoce*: crianças de zero a 3 anos com atraso no desenvolvimento neuropsicomotor. Brasília-DF: Ministério da Saúde, Secretaria de Atenção à Saúde, 2016. 184p. Available at: http://bvsms.saude.gov.br/bvs/publicacoes/diretrizes_estimulacao_criancas_0a3anos_neuropsicomotor.pdf.

eyes include microphthalmia, lens dislocation, cataracts, intraocular calcifications, optic nerve atrophy, hypoplasia, optic nerve pallor, macular pallor, macular chorioretinitis and chorioretinal atrophy[12].

The prognosis for babies with congenital Zika virus infection is currently unknown. However, given all the conditions and anomalies related to the syndrome, health care and clinical monitoring of these babies, regardless of whether or not they have apparent congenital defects, is of paramount importance to ensure proper monitoring[13]. Babies with CZS abnormalities (such as microcephaly, intracranial calcification or other brain or eye abnormalities) require a multidisciplinary team and an established medical clinic to facilitate coordination of treatment. Before the baby is discharged from the maternity hospital, recommended services and continuous follow-up care must be established by sub-specialists[14]. In addition to childcare, they must also be referred for early stimulation in a rehabilitation service provided, for example, by a specialized rehabilitation center, physical medicine rehabilitation center or physical rehabilitation center - intermediate level, intellectual rehabilitation service - and must be accompanied by a physical therapist, phonoaudiologist or occupational therapist[15].

For this entire network of attention and care to really provide the necessary assistance to babies, the families need to receive information about the importance of monitoring their development, as well as psychosocial support so they can face the adversities that will arise with the growth and the discovery of other limitations. And, considering that many of the families with babies in these conditions live in municipalities in the northeastern *Sertão* which do not even have basic sanitation, this entire health care network is distant, making adherence to treatment much more sacrificing and expensive[16].

II. Equity and justice in access to health services

The term "equity" started to receive greater attention in the 1980s, as one of the milestones of the discussion in the field of health based on the strategy formulated by the World Health Organization (WHO) - "Health for All by the Year 2000" -, whose objective was to promote health actions based on the notion of need

[12] CENTER FOR DISEASE CONTROL AND PREVENTION – CDC. *Congenital Zika Syndrome & Other Birth Defects*. Available at: https://portugues.cdc.gov/zika/hc-providers/infants-children/zika-syndrome-birth defects.html. Accessed on: 10 Dec. 2017.

[13] *Id. Ibid*.

[14] *Id. Ibid*.

[15] MINISTÉRIO DA SAÚDE – MS. Secretaria de Atenção à Saúde. *Diretrizes de estimulação precoce*: crianças de zero a 3 anos com atraso no desenvolvimento neuropsicomotor. Brasília-DF: Ministério da Saúde, Secretaria de Atenção à Saúde, 2016. 184p. Available at: http://bvsms.saude.gov.br/bvs/publicacoes/diretrizes_estimulacao_criancas_0a3anos_neuropsicomotor.pdf.

[16] DINIZ, Debora. *Zika*: do Sertão nordestino à ameaça global. Rio de Janeiro. Civilização Brasileira, 2016.

and aimed at reaching everyone, regardless of race, gender, social status and other differences that could be defined socioeconomically and culturally[17].

The most recent debates and conceptual definitions about inequalities and equity in health are essentially supported by the theory of justice formulated by two important contemporary authors, Raws[18] and Sen[19], whose analyzes have influenced the discussion on the theme - though justice and equity are approached based on different perspectives, because the idea of justice carries a distributive meaning, which implies equal opportunities, in view of the different needs of citizens[20].

Due to the multidimensional nature of the concept, Sen[21] understands that equity presupposes not only issues related to the distribution of health care actions, but also the possibility of achieving good health. In contrast, it is known that the inclusion of principles of equity in the formulation of a health policy does not ensure an equal implementation, in the sense of meeting the diversity of needs of the individuals[22]. When health policies fail to meet the needs of individuals in their health needs, the Judiciary is opened up in an attempt to enforce the Constitutional Law of access to health.

The article 6 of the Brazilian CF/88 presents health as a social right, alongside education, work, leisure, security, social security, maternity protection, childhood and assistance to the destitute. Conceptually, equity involves several dimensions and, for this reason, raises a rich debate in its operationalization. It approaches both the principle of equal access (horizontal equity) and the principle of difference, by recognizing the diversity of social subjects' needs (vertical equity). In the scope of health, equity is considered horizontal when it is intended to identify and treat equally people with equal health needs and vertical, when people with different health needs are treated differently[23].

In this way, equity is the ethical basis that must guide the decision-making process for resource allocation. The association of this principle with

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[17] VIANA, Ana Luiza d'Ávila; FAUSTO, Márcia Cristina Rodrigues; LIMA, Luciana Dias de. Política de saúde e eqüidade. *São Paulo Perspec*., São Paulo, v. 17, n. 1, p. 58-68, mar. 2003. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S010288392003000100007&lng=en&nrm=iso. Accessed on: 09 Sep. 2017. https://doi.org/10.1590/S0102-88392003000100007.

[18] RAWS, J. *Uma teoria da justiça*. Tradução de Almiro Pisetta e Lenita M. R. Esteves. São Paulo: Martins Fontes, 2000.

[19] SEN, A. *Desigualdade reexaminada*. Tradução de Ricardo Doninelli Mendes. São Paulo: Record, 2001.

[20] VIANA, Ana Luiza d'Ávila; FAUSTO, Márcia Cristina Rodrigues; LIMA, Luciana Dias de. *op. cit.*

[21] SEN, A. *op. cit.*

[22] VIANA, Ana Luiza d'Ávila; FAUSTO, Márcia Cristina Rodrigues; LIMA, Luciana Dias de. *op. cit.*

[23] CAMPOS, Gastão Wagner de Sousa. Reflexões temáticas sobre eqüidade e saúde: o caso do SUS. *Saúde Soc.*, São Paulo, v. 15, n. 2, p. 23-33, ago. 2006. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-12902006000200004&lng=en&nrm=iso. http://dx.doi.org/10.1590/S0104-12902006000200004.

those of individual and public responsibility and of justice allows asserting the right to health. Recognizing the different needs of different individuals to achieve equal rights is the practical path of ethics that can lead to greater access to health care[24].

III. Public policies to confront the Zika virus

The Ministry of Health has issued protocols for surveillance and health care in response to the occurrence of microcephaly related to infection by the Zika virus, in addition to the protocol for early stimulation of children with microcephaly, and has committed efforts and resources to enforce these protocols. Confronting strategies for microcephaly are divided into three axes: (i) combating the mosquisto-transmitted; (ii) service to people; and (iii) technological development, education and research. An important action is that mothers of children diagnosed with microcephaly and who have a family income per capita less than a quarter of the current minimum wage can apply to receive the Continuous Cash Benefit (BPC), whose the value of which is equivalent to a minimum wage[25]. Law no. 13.301/2016[26] regulates the issue of BPC to families that have a child who is a victim of neurological sequelae due to microcephaly and establishes the receipt of the benefit for a maximum period of three years.

Currently, the concept of disability used is that described in Law no. 8,742/1993[27], ratified by Law no. 13.146/2015 ("Brazilian Law of Inclusion")[28]:

> A person with disability is who has long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on equality of conditions with other persons.

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[24] GARRAFA, Volnei; OSELKA, Gabriel; DINIZ, Debora. Saúde pública, bioética e equidade. *Rev. bioética*, v. 5, n. 1, p. 27-33, 1997. Available at: https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/download/361/462.

[25] HENRIQUES, Cláudio Maierovitch Pessanha; DUARTE, Elisete; GARCIA, Leila Posenato. Desafios para o enfrentamento da epidemia de microcefalia. *Epidemiol. Serv. Saúde*, Brasília, v. 25, n. 1, p. 7-10, mar. 2016. Available at: http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S2237-96222016000100007&lng=en&nrm=iso. Accessed on: 18 Aug. 2017. https://doi.org/10.5123/S1679-49742016000100001.

[26] BRASIL. *Lei n. 13.301, de 27 de junho de 2016*. Dispõe sobre a adoção de medidas de vigilância em saúde quando verificada situação de iminente perigo à saúde pública pela presença do mosquito transmissor do vírus da dengue, do vírus chikungunya e do vírus da zika; e altera a Lei nº 6.437, de 20 de agosto de 1977. Available at: www.planalto.gov.br/ccivil_03/_ato2015-2018/2016/lei/L13301.htm. Accessed on: 18 Aug. 2017.

[27] BRASIL. *Lei n. 8.742 de 7 de Dezembro de 1993*. Dispõe sobre a organização da Assistência Social e dá outras providências. Available at: http://www.planalto.gov.br/ccivil_03/leis/l8742.htm. Accessed on: 26 Aug. 2020.

[28] BRASIL. *Lei n. 13.146, de 6 de julho de 2015*. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). Available at: h http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2015/lei/l13146.htm. Accessed on: 26 Aug. 2020.

This concept broadens the spectrum of people who can be contemplated with the BPC and recognizes the importance of the interaction of body-related impediments with sociocultural barriers that hinder and/or prevent the social participation of people with disabilities[29].

Law no. 13.301/2016 also provides for health surveillance measures that can be determined and carried out to contain the diseases transmitted by *Aedes aegypti* and specifies the measures to be adopted, such as: institution of cleaning activities in real state, with identification and elimination of vector outbreaks; realization of educational campaigns; visits to public and private properties to eliminate mosquitoes and their breeding sites; forced entry into public and private properties, in the event of abandonment, absence or refusal of a person who may allow access by a public agent. The article 3 reiterate other fundamental measures for the containment of the diseases caused by the viruses referred at the *caput*, such as: compliance with the diagnostic criteria established by the current technical standards; improvement of information, notification, research and dissemination systems for data and indicators; universal access to drinking water and sanitation; encouraging the development of scientific research and the incorporation of new health surveillance technologies; among others.

Discussion and Results

I. Difficulties experienced by families in their daily lives

In some of the reports selected in the bibliographic survey, there is a lack of public authority towards families, who often pay for themselves with the purchase of diapers, medicines and the transportation to rehabilitation centers. In a report published by the newspaper *Folha de São Paulo* on July 29, 2016, some of these cases can be seen:

> Luhandra's family, nine months old, had to sell the car and the market, took their children out of private school and moved to Recife, where they live on a salary of R$700. Wiliam's parents, eight months old, charge a subsidy in court to supplement the income of R$900. With just R$250 from *Bolsa Família*, Pérola's mother, ten months old, travels 400 km from Betânia to the capital every week and sleeps in support houses[30].

[29] PEREIRA, Éverton Luís *et al*. Perfil da demanda e dos Benefícios de Prestação Continuada (BPC) concedidos a crianças com diagnóstico de microcefalia no Brasil. *Ciênc. Saúde coletiva*, Rio de Janeiro, v. 22, n. 11, p. 3557-3566, nov. 2017. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232017021103557&lng=en&nrm=iso. https://doi.org/10.1590/1413-812320172211.22182017.

[30] NUNES, Kleber. Pais de bebês com microcefalia vivem abandono e recorrem à Justiça em PE. *Folha de S. Paulo*, 29 jul. 2016. Available at: http://www1.folha.uol.com.br/cotidiano/2016/07/1796583-pais-de-bebes-com-microcefalia-vivem-abandono-e-recorrem-a-justica-em-pe.shtml. Accessed on: 08 Jul. 2017.

According to the report, the families mentioned sought treatment for their babies with microcephaly in up to five different hospitals in Recife. Published a year after the beginning of the case reports - "which gained international repercussion, with an epicenter in Pernambuco" -, the text reports the dissatisfaction of the parents of babies with microcephaly with the "abandonment by the public power, both in the lack of financial resources and medical treatment and psychological support promised by city halls, states and the Union". In addition, these parents needed to share high-cost medication cards and sleep in support homes, depending on the help of family members and non-governmental organizations[31].

According to a news story published on April 7, 2017 by the newspaper *Tribuna Hoje*[32] , Alagoas recorded a lack of anticonvulsant medications, such as phenobarbital and vigabatrin, which are essential for monitoring microcephaly. Despite admitting the problem to the report, the health departments of the state of Alagoas and the municipality of Maceió did not estimate a deadline for the arrival of new lots. The newspaper listened to neurologist Lúcia Helena Reis, who explained that the phenobarbital (Gardenal) takes effect for a maximum of three or four days, while Sabril (vigabatrin) has a faster action (and therefore children must not spend a day without this medication).

Newspaper report from *O Globo*[33] published in January 2016 presents a case in which it was necessary to legally request low-cost medication. The superintendent of the Brazilian Institute for the Rights of Persons with Disabilities (IBDD), Teresa Costa D'Amaral, pointed out to *O Globo* that the institute had, at the time, an action in court for the supply of diapers, talc and anticonvulsant - which, although it was low cost (R$9, according to the report), could not be bid for not being on the list of the health department.

II. From demands to the Judiciary

A large part of the demands presented to the Judiciary are aimed at the purchase of drugs included in the SUS list, but which, for various reasons, are not available in the health system at the time of the patients' need. Low-cost and easy--to-purchase supplies, such as diapers, and items that are beyond the possibilities of acquisition by families have also been judicial zed.

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[31] *Id. Ibid*.

[32] FALTAM remédios para tratar crianças com microcefalia em Alagoas. *Tribuna Hoje*, 07 abr. 2017. Available at: http://www.tribunahoje.com/noticia/207474/cidades/2017/04/07/faltam-remedios-para-tratar-criancas-com-microcefalia-em-alagoas.html. Accessed on 08 Jul. 2017.

[33] D'AMARAL, Teresa Costa. Vítimas da microcefalia e do abandono. *O Globo*, Rio de Janeiro, 31 jan. 2016. Available at: http://noblat.oglobo.globo.com/geral/noticia/2016/01/vitimas-da-microcefalia-e-do-abandono.html. Accessed on: 08 Jul. 2017.

In the judgment of the rapporteur Marcelo Rodrigues, there is a need to acquire one of these items:

> REQUIRED REVIEW 1.0313.13.013658-0/001 - PUBLIC CIVIL ACTION - PATIENT WITH MICROCEPHALY - PATIENT WITH MICROCEPHALY - NEED TO USE A WHEELCHAIR - HIGH COST INPUT - Impossibility to acquire with own resources - Right to health and right to life - Obligation of funding by the Municipality - Joint liability - As evidenced by the patient's need to receive the prescribed input and by not being able to acquire it with his own resources, there was an imposition to compel the Public Power from any sphere, isolated or jointly, to fund it in compliance with the constitutional guarantee of the right to health and right to life (art. 6 of the Constitution of the Federative Republic of Brazil). Refers to the necessary review of the sentence f. 93-94v that, in the records of the public civil action filed by the Public Prosecutor's Office of the State of Minas Gerais, the request to condemn the defendant to the obligation to provide the assisted person with a custom-made wheelchair was well-founded. The action proved to be perfectly possible to compel the Public Power to pay for the acquisition of the input so that the patient can have a dignified life[34].

As children with microcephaly grow, other demands start to emerge, as can be seen in a report published by *Human Rights Watch*[35] on May 15, 2019 that shows that many of these children would turn to 3 or 4 years old in that year and would need nutritional supplements, surgeries, expensive medications, early stimulation to increase cognitive development, orthodontic appliances, among other items and services.

The judgment analyzed by the rapporteur Carlos Levenhagen in the Civil Appeal n. 1.0194.18.000686-9/001, with judgment date on June 27, 2019, corroborates the above, regarding the request for enteral nutrition and apparatus for administering the diet to SUS.

> This is an appeal filed by the State of Minas Gerais against the sentence, which upheld the requests formulated in the ACTION OF OBLIGATION TO DO filed by S.I.S.C., rep/

[34] TRIBUNAL DE JUSTIÇA DO ESTADO DE MINAS GERAIS. Remessa Necessária . 1.0313.13.013658-0/001. Relator:Des. Marcelo Rodrigues. Data do julgamento: 10.out.2017. Available at: https://www5.tjmg.jus.br/jurisprudencia/pesquisaPalavrasEspelhoAcordao.do?paginaNumero=12&linhasPorPagina=1&numeroRegistro=12&totalLinhas=25&palavras=microcefalia&pesquisarPor=ementa&orderByData=2&referenciaLegislativa= Accessed on: 08.Jul.2019.

[35] ZIKA: as famílias esquecidas pelo Brasil. 2019. Human Rigths Watch (HRW). Available at: https://www.hrw.org/pt/blog-feed/zika-familias-esquecidas-pelo-brasil#blog-330365. Accessed on: 08 Jul. 2019.

> by its parent R.I.R.M.S., with resolution of the merits, condemning the defendant to provide to the minor, monthly, under penalty of a daily fine to be fixed in case of compliance with the sentence, the supplement Nutren JR or similar, and Equipos-15, which should last indefinitely, upon presentation of a quarterly medical prescription[36].

The plaintiff of the action is a child of approximately 2 years old, with cerebral palsy of epigastric tetraplegic distribution, oropharyngeal dysphagia (ICD G80.9/ Q02) (microcephaly and cerebral palsy), resulting from congenital Zika syndrome, a fact confirmed by certificates doctors who claimed to be the important supplement for the treatment and the nutritional and immunological improvement of the patient. Before this scenario, the TJMG understood that the applicant's need to obtain supplements had been characterized, in the face of her clinical condition and because her family did not have enough monthly income, and therefore determined that the state of Minas Gerais should bear the costs.

As described in the research report carried out by the CNJ[37] on the judicialization of health in Brazil, the citizen's right to fight for another right before the Judiciary is, in addition to being legitimate, an important element in the configuration of Brazilian health democracy. If, on the one hand, standardized public policies represent important legal guarantees in protecting the right to health, the possibility of the Judiciary to intervene in the realization of that right represents the last guarantee of the citizen against an eventual violation or threat to that right.

III. The scope of assistance recommended by the Ministry of Health

Regarding the policy of care for children with CZS, as recommended by the Ministry of Health and provided in the protocols for surveillance and health care related to infection by the Zika virus, it is necessary to analyze the scope of this assistance, which preferably consists of childcare consultations, early stimulation and specialized care.

Analyzing the *Epidemiological Bulletin* of the Secretariat of Health Surveillance (SVS) of the Ministry of Health[38], with data extracted from the Public

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[36] TRIBUNAL DE JUSTIÇA DO ESTADO DE MINAS GERAIS. Apelação Cível1.0194.18.000686-9/001. Relator: Carlos Levenhagen. Data do julgamento: 27.Jun.2019. Available at:.https://www5.tjmg.jus.br/jurisprudencia/pesquisaPalavrasEspelhoAcordao.do?&numeroRegistro=2&totalLinhas=25&paginaNumero=2&linhasPorPagina=1&palavras=microcefalia&pesquisar. Accessed on: 07.Jul.2019.

[37] CONSELHO NACIONAL DE JUSTICA – CNJ. Relatório Analítico Propositivo. Justiça Pesquisa. *Judicialização da Saúde no Brasil*: perfil das demandas, causas e propostas de solução, *cit.*

[38] MINISTÉRIO DA SAÚDE – MS. Monitoramento integrado de alterações no crescimento e desenvolvimento relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas, até a Semana Epidemiológica 09/2019. *Boletim Epidemiológico*, Brasília-DF, v. 50, n. 8, mar. 2016. Available at: http://portalarquivos2.saude.gov.br/images/pdf/2019/marco/22/2019-001.pdf. Accessed on: 07 Jul. 2019.

Health Events Registry (RESP - Microcephaly), it was found that, of the 2,865 confirmed cases between the epidemiological weeks 45/2015 and 52/2018 (11/8/2015 to 12/29/2018), there was a concentration in the Northeast region, with 1,883 confirmed cases of children with microcephaly.

Of the total cases, 1,739 (60.7%) received care in childcare, that is, standard care in the basic health unit, which encompasses any and all children - that is, they were not specific consultations for congenital Zika syndrome. Early stimulation consultations were performed in 1,000 of the 2,865 (34.9%) confirmed cases, that is, much less than half of the affected children were having the necessary follow-up with one of the primary therapies to aid their integral development. As seen in the newspaper reports previously presented, difficulties with transportation and the displacement of families who live far from assistance centers are probably factors that prevent adherence to treatment. In turn, specialized care occurred in 1,828 of the 2,865 (63.8%) confirmed cases.

Considering only confirmed cases, approximately 71.9% of them reported some type of care. All three types of care - childcare, early stimulation and specialized care - were reported in 831 cases, that is, 29% of the children were effectively receiving full treatment as proposed by the Ministry of Health. In turn, the association between childcare services and specialized care was reported in 688 cases, which means that 24% of children were able to receive care in these two types of services.

There is a low coverage of care for children with regard to both childcare and early stimulation and specialized care. However, the insufficiency of the coverage of the three types of care needed to monitor the psychoneuromotor development of these children is highlighted.

Final Considerations

Despite the efforts made regarding the construction of specialized centers, the training and continuing education of health professionals for the knowledge and specific care for these children, it appears that most of them are not receiving the care and assistance according to as recommended by competent bodies.

Although it is known that the signs and symptoms resulting from the congenital Zika syndrome are not curable, it is important to monitor children in both early stimulation and childcare - especially as a reference and support for parents who have doubts, many still without answers. During these visits, these fathers and mothers can learn to deal with their children and to assist them properly; such knowledge ranges from how to administer controlled substance to care in handling, cleaning and administering food by gastric tube, in addition to the safe way to act during frequent seizures, in order to prevent other injuries - in short, support minimum so that they can know the limitations of children and deal with them.

Another point to be questioned is the temporary nature of the Continuous Cash Benefit (BPC), provided by the Organic Law on Social Assistance (Law No. 8.742/1993), which guarantees a minimum wage for disabled person and the elderly who have no means to provide maintenance itself or to have it provided by the family. Law no. 13,301/2016 provides, unconstitutionally, the payment of this benefit for only three years in cases of children with microcephaly, disregarding that these children have limitations and sequelae that will have significant influence throughout their lives, and not only in the first three years.

In addition to assistance in rehabilitation centers, social assistance and BPC in the form of permanent pensions - as is expected to happen after re-entering the agenda of the Federal Supreme Court -, children with congenital syndrome caused by the Zika virus need a support network that goes beyond health and rehabilitation aspects. One cannot fail to consider the aspects relevant to education, so that it is able to accept diversity and enable real inclusion in the perspective of human rights. Soon they will be schoolchildren, and the education sector needs to be prepared to welcome them, not only in terms of structural adequacy, but mainly in the continuing education of teachers, who will need to be able to deal with them.

The infection of people with the Zika virus started in Africa and now resurfaces in the Americas from poverty, misery, lack of decent housing conditions and, above all, life. There is an urgent need to question and resolve structural problems, such as universal access to treated water, adequate collection and disposal of waste, expansion of basic sanitation, universality and equity in access to health services and so many other issues of a social, economic and political nature.

Essential guarantees for the protection of the right to health in Brazil run through well-planned and implemented public policies within the scope of SUS. These are the policies that define the concrete legal content of the right to health, by defining which services and products will be available for citizens to promote, protect and recover their health[5]. And when they are ineffective, judicialization ends up being the only possibility for the realization of citizens' rights.

Much remains to be discovered about Zika infection; the risks of sexual transmission and subsequent vertical transmission are among the most worrying issues. It is necessary to recognize that the urgency of care and protection is not limited to eliminating the mosquito-borne; it also includes caring for women and children already affected. And, due to the state of helplessness and uncertainty experienced by these mothers, it is necessary to raise measures for the integral protection of women's reproductive health, from access to contraceptive methods to safe abortion. It is therefore urgent to recognize that taking care of women's reproductive health is taking care of public health[39].

[39] DINIZ, Debora. *op. cit.*

References

BARDIN, Laurence. *Análise de conteúdo*. Lisboa: Edições 70, 2010.

CAMPOS, Gastão Wagner de Sousa. Reflexões temáticas sobre eqüidade e saúde: o caso do SUS. *Saúde Soc*., São Paulo, v. 15, n. 2, p. 23-33, ago. 2006. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-12902006000200004&lng=en&nrm=iso. http://dx.doi.org/10.1590/S0104-12902006000200004.

CENTER FOR DISEASE CONTROL AND PREVENTION – CDC. Congenital Zika Syndrome & Other Birth Defects. Available at: https://portugues.cdc.gov/zika/hc-providers/infants-children/zika-syndrome-birth defects.html. Accessed on: 10 Dec. 2017.

CONSELHO NACIONAL DE JUSTICA – CNJ. Relatório Analítico Propositivo. Justiça Pesquisa. *Judicialização da Saúde no Brasil*: perfil das demandas, causas e propostas de solução. INSPER.2019. Available at: http://cnsaude.org.br/wpcontent/uploads/2019/07/JUDICIALIZAC%CC%A7A%CC%83O-DA-SAU%CC%81DE-NO-BRASIL.pdf. Accessed on: 10 Jul. 2019.

D'AMARAL, Teresa Costa. Vítimas da microcefalia e do abandono. *O Globo,* Rio de Janeiro, 31 jan. 2016. Available at: http://noblat.oglobo.globo.com/geral/noticia/2016/01/vitimas-da-microcefalia-e-do-abandono.html. Accessed on: 08 Jul. 2017.

DINIZ, Debora. *Zika*: do Sertão nordestino à ameaça global. Rio de Janeiro. Civilização Brasileira, 2016.

FALTAM remédios para tratar crianças com microcefalia em Alagoas. *Tribuna Hoje*, 07 abr. 2017. Available at: http://www.tribunahoje.com/noticia/207474/cidades/2017/04/07/faltam-remedios-para-tratar-criancas-com-microcefalia-em-alagoas.html. Accessed on 08-07-2017.

FEITOSA Ian Mikardo Lima; SCHULER-FACCINI, Lavinia; SANSEVERINO, Maria Teresa Vieira. Aspectos importantes da Síndrome da Zika Congênita para o pediatra e o neonatologista. *Bol Cient Pediatr.*, v. 5, n. 3, p. 75-80, 2016. Available at: https://www.sprs.com.br/sprs2013/bancoimg/170118173954bcped_05_03_a02.pdf.

GARRAFA, Volnei; OSELKA, Gabriel; DINIZ, Debora. Saúde pública, bioética e equidade. *Rev. bioética,* v. 5, n. 1, p. 27-33, 1997. Available at: https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/download/361/462.

HENRIQUES, Cláudio Maierovitch Pessanha; DUARTE, Elisete; GARCIA, Leila Posenato. Desafios para o enfrentamento da epidemia de microcefalia. *Epidemiol. Serv. Saúde*, Brasília, v. 25, n. 1, p. 7-10, mar. 2016. Available at: http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S2237-96222016000100007&lng=en&nrm=iso. Accessed on: 18 Aug. 2017. https://doi.org/10.5123/S1679-49742016000100001.

MINISTÉRIO DA SAÚDE – MS. Monitoramento integrado de alterações no crescimento e desenvolvimento relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas, até a Semana Epidemiológica 09/2019. *Boletim Epidemiológico*, Brasília-DF, v. 50, n. 8, mar. 2016. Available at: http://portalarquivos2.saude.gov.br/images/pdf/2019/marco/22/2019-001.pdf. Accessed on: 07 Jul. 2019.

MINISTÉRIO DA SAÚDE – MS. Secretaria de Atenção à Saúde. *Diretrizes de estimulação precoce:* crianças de zero a 3 anos com atraso no desenvolvimento neuropsicomotor. Brasília-DF: Ministério da Saúde, Secretaria de Atenção à Saúde, 2016. 184p. Available at: http://bvsms.saude.gov.br/bvs/publicacoes/diretrizes_estimulacao_criancas_0a3anos_neuropsicomotor.pdf.

MINISTÉRIO DA SAÚDE – MS. Secretaria de Atenção à Saúde. *Protocolo de atenção à saúde e resposta à ocorrência de microcefalia relacionada à infecção pelo vírus Zika* [recurso eletrônico]. Brasília-DF: Ministério da Saúde, Secretaria de Atenção à Saúde, 2016. Available at: https://www20.anvisa.gov.br/segurancadopaciente/index.php/publicacoes/item/protocolo-de-atencao-a-saude-e-resposta-a-ocorrencia-de-microcefalia-relacionada-a-infeccao-pelo-virus-zika.

NEVES, Maria do Céu Patrão. Alocação de recursos em saúde: considerações éticas. *Bioética*, v.7, n. 2, p. 155-163, 1999. Available at: https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/download/307/446.

NUNES, Kleber. Pais de bebês com microcefalia vivem abandono e recorrem à Justiça em PE. *Folha de S. Paulo*, 29 jul. 2016. Available at: http://www1.folha.uol.com.br/cotidiano/2016/07/1796583-pais-de-bebes-com-microcefalia-vivem-abandono-e-recorrem-a-justica-em-pe.shtml. Accessed on: 08 Jul. 2017.

PEREIRA, Éverton Luís et al. Perfil da demanda e dos Benefícios de Prestação Continuada (BPC) concedidos a crianças com diagnóstico de microcefalia no Brasil. *Ciênc. Saúde coletiva*, Rio de Janeiro, v. 22, n. 11, p. 3557-3566, nov. 2017. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232017021103557&lng=en&nrm=iso. https://doi.org/10.1590/1413-812320172211.22182017.

RAWS, J. *Uma teoria da justiça*. Tradução de Almiro Pisetta e Lenita M. R. Esteves. São Paulo: Martins Fontes, 2000.

SEN, A. *Desigualdade reexaminada*. Tradução de Ricardo Doninelli Mendes. São Paulo: Record, 2001.

VENTURA. M. *Direitos reprodutivos no Brasil*. 3. ed. São Paulo: Câmara Brasileira do Livro, 2009.

VIANA, Ana Luiza d'Ávila; FAUSTO, Márcia Cristina Rodrigues; LIMA, Luciana Dias de. Política de saúde e eqüidade. *São Paulo Perspec.*, São Paulo, v. 17, n. 1, p. 58-68, mar. 2003. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S010288392003000100007&lng=en&nrm=iso. Accessed on: 09 Sep. 2017. https://doi.org/10.1590/S0102-88392003000100007.

WORLD HEALTH ORGANIZATION - WHO. Zika: the origin and spread of a mosquito-borne virus. *Bulletin of the World Health Organization*, n. 94, p. 675-686, 2016. Available at: http://www.who.int/bulletin/volumes/94/9/16-171082.pdf. Accessed on: 12 Aug. 2017.

ZIKA: as famílias esquecidas pelo Brasil. 2019. Human Rigths Watch (HRW). Available at: https://www.hrw.org/pt/blog-feed/zika-familias-esquecidas-pelo-brasil#blog-330365. Accessed on: 08 Jul. 2019.

Alessandra Alves de Vasconcelos - Master in Health Sciences by *Universidade de Brasília* (UnB); specialization in Collective Health with emphasis on Health Education by UnB; specialization in Bioethics by UnB; undergraduate in Nursing and Obstetrics by UnB; undergraduate student in Law by Centro Universitário Newton Paiva. Belo Horizonte/MG, Brasil. E-mail: alessandravasconcelos.adv@hotmail.com

Luciana Dadalto - PhD in Health Sciences by *Faculdade de Medicina de Minas Gerais;* Master in Private Law by *Pontifícia Universidade Católica de Minas Gerais* (PUC Minas); Undergraduate in Law by PUC Minas. Coordinator of the Group of Studies and Research on Bioethics (GEPBio) of the Escola de Direito do Centro Universitário Newton Paiva. Belo Horizonte/MG, Brasil.

Marcelo Sarsur - PhD in Law by *Universidade Federal de Minas Gerais* (UFMG); Master in Law by UFMG; Undergraduate in Law by UFMG. Associate Professor at the *Centro Universitário Newton Paiva*. Belo Horizonte/MG, Brasil.