

Associations of mothers and family members affected by congenital Zika virus syndrome: profile and main related discussions

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Abstract: In Brazil, the impact of consecutive health emergencies in the last five years, such as the Zika epidemic (2015) and the COVID-19 pandemic (2020), acutely affected families of children with congenital Zika syndrome (CZS). This article explores epidemic processes that replicate the intersections of disability, care, gender, class and race, and proposes the construction of a profile of civil associations of mothers and families of children with CZS, as well as their mobilizations, especially the União Mães de Anjos (UMA). Based on the literature on the topic, interviews and workshops with mothers of children with CZS linked to associations in different parts of Brazil, it was observed that epidemics produce unequal impacts in relation to age, race, class, gender, location and disability. While the impacts of health emergencies can be ongoing for people living at the intersection of multiple oppressions, we highlight resistance in the form of organizational capacity to navigate access to rights and reconfigure power dynamics.

► **Keywords:** Congenital Zika virus syndrome. COVID-19. Mothers' associations. Brazil.

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Introduction

In this article, we are interested in the composition of profiles and agendas, as well as the problematization of internal survival strategies and solidarity networks established by associations of mothers and family members affected by congenital Zika virus syndrome (SCZV). A political and social geography of such associations is observed, their sanitary and territorial interdependencies, understanding that, in epidemics, the actions of different characters and institutions elucidate power games, political and economic weaknesses. The women and family members of the associations make their conditions precarious, situations that stimulate action. Their bodies together in associations, media and public spaces mobilize views, exercising the plural and performative right to express their needs, as part of a democratic struggle (Butler, 2018).

From this perspective, we tension two contexts. The first, related to the Zika epidemic between 2015 and 2017, in which the first mothers and family associations were created in Brazil. The second, with the COVID-19 pandemic, between 2020 and 2021, which brought new challenges for associations. We constructed a general overview of the state associations of mothers and family members affected by SCZV, highlighting the work of the União Mães de Anjos (UMA) of Pernambuco and the Frente Nacional, an organization that stood out for bringing together the presidents of state associations in support of federal agendas such as the compensatory pension (Matos *et al.*, 2019).

A systematic mapping and analysis of these associations, their dynamics, agendas, similarities and differences deserve greater depth. Thinking about reducing this gap, we aim to present the profile of the associations, as well as the women and family members who make up them. For this, as a methodology, we started with a survey, bibliographical discussion and systematic survey of information published on the associations' social networks, creating a database with basic information about the associations, location, main agendas, events, leaders and other variables. Furthermore, to cover the first-time frame, linked to the Zika epidemic (2015-2017), we used interviews and notes from field notebooks produced in meetings with women/mothers from the associations in workshops, conversation circles and focus groups, part of the research material collected within the scope of the "Women's social movements and the response to Zika" project,¹ developed by the team between 2017 and 2019, and approved by the Research Ethics Board, number 2.400.856.

In the second time frame, during the COVID-19 pandemic, we updated the association data collection and identified the opening of new associations. We use data and information produced by associations on their social networks and through informal conversations via WhatsApp. Such conversations were mediated within the scope of actions by researchers involved in work on the SCZV, who were called upon by the leaders of the associations to provide guidance in relation to public policies proposed during that period and which strongly affected the lives of their children and, consequently, the entire family dynamics, especially mothers. As a means of crossing this dialogue, we manage the legislation related to SCZ, namely: Continuous Payment Benefit (CPB), Bolsa Família, Minha Casa Minha Vida and the processes for formulating Bills on compensatory pensions.

We highlight the female role in composing the agenda and dialogues with public authorities, giving new meaning to concepts and ways of acting on the Zika virus epidemic. The leading role assumed by mothers reveals the desire to become visible and thereby gain notoriety and trust, becoming important political actors who wish to break the transience of demands in institutionalized political representations.

Epidemics and associations of mothers and family members affected by SCZV

Epidemic diseases act as a magnifying glass that highlights fears, prejudices, norms and stereotypes about sick people, the human body, gender, ethnic groups and social classes. The variety of perceptions, practices and testimonies that emerge in epidemics show that the disease is not just a biological factor that is the sole responsibility of doctors (Cueto, 1997). Society takes part in the debate and demands answers and various actors mobilize to construct them.

As one of the mobilized actors, the media materialize and mediate this dialogue. This is what Vilella and Natal (2014) call power games and representations. In this sense, there is a dramaturgy of the epidemic that mobilizes different actors, who act on the event in different ways, creating metaphors and frameworks (Sontag, 1989; Rosenberg, 1977; Wald, 2008). In these “epidemic dramas”, there are power struggles, knowledge production and public debates. And, currently, the big arena has been the media and social media. The affected population is often stigmatized, silenced and taken as an “object of study”. Such groups react, organizing themselves into movements and associations, creating specific agendas to dialogue with public bodies.

In a global context, epidemic risks are assumed by national or international institutions, the so-called transnational risk managers, becoming political forces that transform the world. In the face of risk, solutions are built on a combination of surveillance systems, coping plans and information sharing through networks to contain emerging risks. From then on, a sense of sociopolitical urgency is widespread, causing a multiplicity of responses (Beck, 2008).

As is known, in November 2015, the Ministry of Health (MH) declared the Zika virus epidemic associated with the microcephaly outbreak as a public health emergency of national importance (ESPIN). However, this story begins in mid-August 2015, when obstetricians and neonatologists, especially in the Northeast, observed an increase in the number of children with malformations. Doctors alert the Secretariat of Public Health and, later, in October, the Ministry of Health. In November 2015, for the first time since the creation of this legal mechanism, a state of emergency was declared in the country. The Zika virus presented itself as a security threat and a risk event (Nunes; Pimenta, 2016).

In February 2016, the World Health Organization (WHO) declared an international emergency. This emergency scenario is permeated by political events, notably the impeachment process of President Dilma Rousseff and the holding of the Olympics. A situation of great media repercussion, accompanied by social panic. In 2017, SCZV cases decreased significantly. The WHO and the Brazilian government declare the end of the emergency (Diniz, 2016). The Zika epidemic and microcephaly gradually disappeared from newspaper headlines, partly due to the political crisis that Brazil was going through and the feeling of security that the reduction in Zika cases brought (Carvalho, 2016).

With the declaration of the end of the emergency, funding aimed at SCZV disappears, but the demands of children, mothers and families remain and transform as the children grow. It is the associations that remain and create alternatives to keep assistance policies alive and fight bravely to be heard by the State. But after all, who are the women mothers who work in the associations?

Socioeconomic profile of women/mothers affected by the Zika virus epidemic

According to the Ministry of Health (Brazil, 2017),² the socioeconomic profile of people affected by the Zika epidemic is: 71.4% mothers between 15 and 29 years

old; 70.6% mothers with more than eight years of education; 84.3% mothers with brown or black skin color and 49.4% single, separated or widowed mothers. This profile is corroborated in studies (Freitas *et al.*, 2019; Souza *et al.*, 2018; Diniz, 2017) that indicate that women affected by SCZ belong to the least disadvantaged social classes, most of whom identify themselves as women without white, with low education and low per capita income, live in peripheral areas, in housing in precarious conditions, facing problems with sanitation and have had to leave their jobs to take care of their children, who need an intense daily work routine.

Thus, we can say that women, young people, poor people, black people and heads of families were the most affected by the virus. This profile generated stereotypes about women in the media and they were somehow blamed for the epidemic outbreak. Lima (2016) shows that journalistic coverage of the epidemic focuses on women-mothers and can be thought of according to the following categories:

- 1) Guidance: mothers and their variations of the term were asked to be guided by the material - they received tips to protect themselves from the virus or received information that explained the importance of their participation in this process of combating microcephaly;
- 2) Statistics: mothers and their variations of the term appear as numbers, in counts of pregnant women with Zika, in analyzes of the increase in the number of cases of microcephaly in pregnant women, in evaluation of the average age of the mother who contracts the virus;
- 3) Object of research: mothers and their variations of the term appeared as people being researched and genetically mapped - they served as biological sources of information and were analyzed psychologically by observations of others;
- 4) Source of information: mothers and their variations of the term were used as a source of information, that is, their statements and experiences helped in the construction of the material (Lima, 2016, p. 47-48, free translation).

This categorization points out that, despite women being seen as protagonists in the journalistic plot, they were not called upon to speak. The sources used were generally provided by scientists and/or government bodies. The press legitimized patriarchal discourses, ideal types of motherhood, took women as research objects and contributed to the dissemination of feelings of guilt and fear (Lima, 2016). In this universe of uncertainties associated with the lack of definition of public policies, women-mothers create groups for mutual assistance, exchanging experiences and

information. They form an important network and establish a bridge of dialogue between society, science and public authorities (Lima, 2016).

Context of creation of associations, characteristics and identity impasses

In order to outline the profile of the associations, a map was created by one of the authors, as a visual interpretation of a database on SCZV mothers and family associations active until 2019. The database was created by the same author through documentary research on active social media and web pages of Zika associations. From the map, it can be seen that since the beginning of the epidemic outbreak until the first half of 2020, 21 civil associations were created. Most of them emerged between 2016 and 2017, during the epidemic and the period immediately after. A new wave of associations was observed at the end of 2018 and in 2019 and 2020. The new waves mark the creation of associations beyond the northeast axis.

There is internal tension in associations about restricting themselves to treating cases of microcephaly, or expanding to rare diseases. This tension impacts the groups' identity processes and the configuration of sociability networks. One of the nucleus of the tension is the fact that access to care policies for children with SCZV is associated with the diagnosis of microcephaly. Furthermore, some women highlight the specificities of the disease. Scott *et al.* (2017) show that these tension lines persist throughout the daily lives of families and in care systems (Scott *et al.*, 2017; Lira, 2017). Also noteworthy is the emergence of the National Front for Congenital Zika Virus Syndrome, in 2017, with the aim of discussing nationally the direction of health and assistance policies aimed at these families, such as Provisional Measure nº 894/2019, which discussed the granting of a special pension for children with SCZV, which became Law No. 13,985, of April 7, 2020.

As we can see in the following figure, more than 76% of associations are concentrated in the northeast and north of the country, revealing the prevalence in territories marked by the absence of basic services, such as health and sanitation. In the presidencies of associations, female leaders stand out, which partly explains why there is a tendency for women, particularly mothers and grandmothers, to be responsible for caring for children. Not all organizations are regulated by a legal construct. However, they play an important role in helping and guiding their members.

Figure 1. Map of SCZV mothers and family associations active until 2019



Source: own elaboration.

The dimension of religiosity in associations

The religious issue is very present in associations, a fact that can be observed in their names, which mention God, “angels”, “blessings”, “faith” etc. Generally, children with SCZV are presented as a divine gift. Furthermore, in a scenario of abandonment, mothers find comfort and assistance in churches. In other words, in the absence or delay of response from science and public authorities, current religion as an institution that produces responses, reception and care.

The religiosity of the groups directly implies discussions linked to women's reproductive rights and the issue of abortion (Carvalho, 2018). In most associations, there is a pro-life mobilization. In other words, it is also a political position, a moral dilemma that is used as a basis for public policies and research in the area. According to Scott *et al.* (2017), failure to align the abortion agenda with feminist groups can ideologically alienate funding institutions with feminist agendas.

However, other nuances can be perceived in the relationship between SCZV and abortion, as observed by Luciana Lira *et al.* (2018), as there are countless reports of women who in their prenatal care were formally advised to have an abortion under the argument that their children “would not live”, “would not survive the first year of life” or would be like “vegetables”. They state that the notion of right to life is related to the search for valuing the right to life of children with SCZV, who are sometimes denied the status of a person. Reports inform that, for these women, the debate should revolve around expanding the rights of their children, that is, it is necessary to “take care of the living” (Lira; Meira; Campos, 2018). The authors conclude that:

[...] the rhetoric of the different groups and feminist movements finds little resonance with regard to sexual and reproductive rights in groups of *micro* mothers when they include as their flagship the defense of the rights of women caregivers to abortion, since they are talking about a reality that is already given to them, and talking about abortion in these circumstances sounds like denying these women's sons/daughters the right to life and their own status as a person, which, at the same time, would deny these women the identity projects they built around the condition of *micro* mothers, special mothers or rare mothers. According to this interpretation, the personhood of children with CZS and their mothers-caregivers is denied, in accordance with the notion of extensive identity used several times in the ethnographic context of the research (Lira; Meira; Campos, 2018, p. 11, free translation).

The arrival of a child with SCZV inserted them not only into political discussions about people with disabilities, but made them reflect on gender, machismo, race and the feminization of care. Germana Soares (UMA), in an interview published in 2018, in the journal *Revista Antropológicas*, reported that the birth of her son Guilherme, who has SCZV, was a watershed that allowed her to learn about several struggles to the point where she currently declares herself as a feminist (Matos; Lira; Meira, 2018). Based on this new identity, Germana Soares works critically with other mothers on issues such as institutional racism, ableism, women's exclusive responsibility for raising and supporting their children, and paternal abandonment.

In this way, using intersectionality in the grassroots activism of associations can provide information about the driving forces, direction and overlap between Brazilian social movements in the context of health emergencies. According to Perry (2016, p. 94, free translation), “Black women's activism illustrates the ways in which the grassroots movement has advanced our understanding of intersectional identity formation in relation to the material interests of marginalized communities in Brazil.”

These material interests are present in the activism of association members through the intersection between disability and care. They state that one of the objectives of the fight is also to highlight the rights of other generations of people with disabilities (Scott *et al.*, 2017). Parental activism is nothing new, of course. However, previous movements of parents of children with disabilities in Brazil were led by white, middle-class parents (Block; Cavalcante, 2014). The fact that they are black, poor and young women is the great “news” of these associations that expand discussions around their rights and give new meaning to their place in society.

The União Mães de Anjo: more than an association, a MOVEMENT

União Mães de Anjo (UMA) was created in December 2015 by two women from Recife, Germana Soares and Gleyse Kelly, mothers of children with microcephaly. They met in line at Oswaldo Cruz Hospital and, during the wait, they shared their doubts, desires and needs. From this meeting, they decided to bring together women-mothers who were going through the same situation and created a discussion forum on WhatsApp, an important space for sociability and information exchange (Scott *et al.*, 2017; Diniz, 2016; Silva; Jorente, 2018).

UMA was born from the WhatsApp group, with the aim of bringing together mothers linked to the microcephaly outbreak, with CNPJ made official in May 2016. UMA plays a prominent role in public policy demands for affected children and collects food, diapers, hygiene, basic food baskets and other needs. It is recurrent in the association's president's speech that UMA's objective is to politicize mothers to achieve public policies. Currently, UMA has approximately 400 members in Pernambuco and the WhatsApp groups have the participation of mothers from other Brazilian states. Although the headquarters are in Recife, UMA has a network with 14 support points in all regions of Pernambuco, geographically distributed in

three areas: Coastal (Recife, Ipojuca), Agreste (Limoeiro, Cortês, Caruaru, Belo Jardim and Arcoverde) and in the Sertão (Serra Talhada and Salgueiro).

On their Facebook page, they have approximately 15,000 followers. They also have accounts on Instagram and Twitter, their own website and YouTube channel, but Facebook is the group's busiest network. There you will find hundreds of videos, surveys of agendas, events, electoral campaigns, donations, news about research, information about rights. There are also photographs and advertisements linked to the pharmaceutical industry and other private institutions that highlight the association's connection with academia and the pharmaceutical industry, outlining the different interests surrounding the disease, the political and financial dimensions. These relationships define the profile and activities of the association. In the case of UMA, there is a symbiosis between an association with a business model and another focused on mutual aid (Barbosa, 2015).

According to Barbosa (2015), most of the people who engage in the challenges of biomedicine are middle-class white people, educated and with a great capacity for mobilization on social networks, whether in person or on the internet. UMA deviates from this rule and is made up of poor, black women with little education. This group of women can be analyzed within the black feminist movement, constituted in the context of multiracial, multicultural and racist societies such as Latin American societies, and its main articulating axis is racism and its impact on gender relations, since that it dictates the gender hierarchy itself in society (Carneiro, 2011).

UMA presents additional intersections between race, disability, and gender, which links the disability rights movement and the black feminist movement. In this sense, they demarcate and establish a new political, cultural, communicational and epistemological place within the Brazilian feminist movement itself. Black women as identity and political subjects are the result of an articulation of heterogeneities, resulting from historical, political, cultural demands, to face the adverse conditions established by Eurocentric Western domination throughout the three centuries of slavery, colonial expropriation and racialized modernity and racist world we live in (Werneck, 2016). It is possible to visualize, within these articulations, the different possibilities that black women have resorted to, the different repertoires or assumptions of (self) identification or identity and political organization. Such possibilities come from the recognition that we are faced with different historical and political agents – black women – intense as all diversity (Werneck, 2016).

In addition to this agenda, the struggle of this group, represented by the president, to participate in scientific events that present the results of research carried out in Brazil on SCZ is highlighted. When present at academic and scientific seminars and conferences, women claim that the disease has completely altered their lives and that they are treated by scientists and journalists as objects of research, and not as human beings. Therefore, they claim the right to participate in all processes of building responses to the disease, as they are the most knowledgeable about the effects of the virus on their children.

An example of this is UMA's speech in September 2018, during the 54th Congress of the Brazilian Society of Tropical Medicine (BSTM), in Recife-PE. Germana, president of UMA, sent a public letter to the BSTM. The letter was welcomed and delivered by the president herself during the Congress; the reading of the letter at the event was recorded and published on the association's Facebook.³ In the letter, Germana defines herself as the mother of a disabled child, woman, black, poor, divorced, head of the family, source of inspiration and research material. Germana claims the right to participate in the production of knowledge about the disease and to know the results of research presented at congresses, as they are results obtained from the bodies of her children. She suggests the use of languages other than scientific, for better understanding, and points out ethical issues, which are often disrespected in studies on the disease.

In response, BSTM published an official note on its website.⁴ In this, it judges the tone of the letter to be aggressive, stating that over sixty years the BSTM has developed studies, congresses, meetings and research into endemic diseases in the search for solutions and harm reduction for neglected populations. It recognizes the failure of not having previously opened the planning of the scientific program so that UMA could be present, interacting with the group. And it highlights the importance of social movements in achieving public health. Finally, it is committed to addressing the issues raised by UMA and guarantees its participation in the Brazilian Social Forum to combat infectious and neglected diseases, held in Belo Horizonte in 2019. However, UMA goes further, it does not want to participate in a forum or pre-congress event, but want to be “inside” the congress itself. How can we do it more systematically when the registration fee alone is approximately R\$500? This fact puts the spaces for disseminating scientific results on the agenda.

Germana, as a representative of a civil association linked to social movements, recognizes herself and assumes a certain social locus and creates tools to confront institutional silences. She shows that speaking is not restricted to the act of uttering words, but of existing. She represents a specific group of women who have traditionally been on the margins of society and demand the right to citizenship. Germana's body-action can be read as an individual who takes her precarious condition as her stimulating function. There is an indexical force in her body that arrives with other bodies in a visible zone for media coverage (Butler, 2018). She exercises, together with her collective of women, “a plural and performative right to appear, a right that affirms and establishes the body in the middle of the political field” (Butler, 2018, p. 17).

It is a collective of women marked by intersectionalities, as we have seen, of non-white, poor and young women who recognize this identity as a political position that involves solidarity and the organization of demand agendas with public authorities. The intersectionality that these women experience reveals the differentiated access they receive from the State, as well as highlighting the power relations within our society that produce the exclusion of certain social groups.

Another important event in the debate on greater participation, in the shaping of research and in decision-making processes in the shaping of public policies, was the creation, in August 2018, of the National Front for the Rights of People with Congenital Zika Virus Syndrome (NFRPCZVS).

The National Front for the Rights of People with Congenital Zika Virus Syndrome

At the time of its creation, the Front was led by Germana Soares (UMA), Ingrid Graciliano, Valdinei Santos da (APAB-BA), Ricardo Moraes (AMACRIM), Rochelle dos Santos (AMIZ), Tamires Sarfésil (Lótus), Alessandra Hora (AFAEL), promoting an interesting national articulation. As previously mentioned, some associations assist children with other rare diseases, in addition to microcephaly. However, from 2017 onwards, the term “congenital Zika virus syndrome” began to gain more space in the speeches of association presidents. As the identity arising from disability (rare disease and/or microcephaly) and the experiences generated by it were not specific (Matos, 2018), associations began to use this term in some spaces and documents, mainly those linked to public policies.

Although families continue to use the term “microcephaly”, with the creation of the NFRPCZVS, one can notice the device of changing the terms, sometimes microcephaly in everyday life, for SCZV in spaces of political dispute. This appointment is political and is part of the process that aims to distinguish microcephaly due to genetics and STORCH (syphilis, toxoplasmosis, rubella, cytomegalovirus, herpes simplex), as the NFRPCZVS understands that SCZV is a condition resulting from Brazil's negligence in controlling *Aedes aegypti*, promoting basic sanitation and supplying drinking water and, as a result, it lacks specific public policies. In this sense, it became important for these families to highlight that until the arrival of the SCZV, disability had never been a possible equation, making it necessary to consider the exceptionality of this situation when formatting public health and social assistance policies (Matos; Quadros; Silva, 2019).

The NFRPCZVS emerged amid criticism from associations regarding the format of the “Feira de Soluções para a Saúde – Zika” event, in Salvador-BA, in 2017. The criticism resided in the search for more effective participation of families affected by SCZV in the configuration of the event, in choosing the programming and in the construction and/or validation of the solutions presented at the Fair (Silva; Matos; Quadros, 2017).

The main purpose of the Front is:

[...] combine the strength and expertise of its members, building a national framework of demands focusing on national health policies, assistance, education, mobility, housing, etc., in the search for dialogue with the federal legislature, ministries and national executive. The National Front does not have its own headquarters and debates are held virtually via the WhatsApp messaging application. This WhatsApp group, in addition to serving as a discussion forum on national demands, also serves to exchange information about treatments, therapies and specificities of each State and association, and is also an important sociability platform where families talk about their daily lives, gains and developments of their children and comfort themselves in cases of hospitalizations and deaths of children (Matos, 2018, p. 5, free translation).

Other topics widely discussed at the Front deal with public policies for caregivers of people with SCZV, Continuous Payment Benefit (CPB), Bolsa Família, Minha Casa Minha Vida, the formulation of Bills on compensatory pensions, discussions on ethics in research, gender, abortion and family reconfigurations as a result of the epidemic, etc. (Matos; Silva, 2020b).

Since its inception, the Front has prioritized discussions on the contradictions of the CPB, claiming that even though Ordinance No. 58, of June 3, 2016,

granted priority to children with SCZV for access to the CPB, it did not modify contradictions historical factors for its concession, such as the fact that family income cannot exceed 1/4 of the minimum wage per person. The result is that countless people with disabilities become ineligible because of this cap. Other contradictions persisted after the publication of this ordinance and prohibit the accumulation of CPB with other benefits (Matos; Quadros; Silva, 2019).

As the CPB was exclusionary and did not respond to the minimum demands of families, the Front began its political participation seeking to make it more inclusive. On March 28, 2018, the Front met with the then Minister of Social Development (MDS), Osmar Terra, and his Executive Secretary, Alberto Beltrame, in Brasília, to discuss the inconsistencies of the CPB. The minister pointed out the difficulties in modifying the CPB criteria, considering that it would need to be discussed through a Constitution Amendment Project (PEC) and was more open to the Front's proposal to include children with SCZV in the regime of lifetime compensation pension from the Union, along the lines of those granted to those affected by the nuclear accident with cesium 137 in Goiânia (GO), the drug thalidomide, hemodialysis in Caruaru (PE) and people who had leprosy and were subjected to isolation and compulsory hospitalization between the years 1930 and 1962.

After this first round of discussions with the national Executive, the Front began the debate with the federal Legislature and met, on 5/9/2018, in Brasília, with Senator Lindbergh Farias and the rapporteur of the Senate Bill (PLS) nº 452, ⁵ Senator Lídice da Mata (PSB-BA), to debate points to be improved in the PLS. In general terms, the NFRPCZVS managed to make several changes to PLS nº 45. However, after Technical Note nº 29/2018, from the National Social Security Institute (INSS), “the opposite position was adopted, as it was understood that it does not correspond to the solutions that the situation requires and evaluates the financial impact of the special pension with high potential” ⁶ and the PLS was archived at the end of the legislature, as recommended by the Internal Regulations.

After a period without answers from the MSD, in September 2019, under the administration of Jair Messias Bolsonaro, Provisional Measure 894/2019 was approved, without in-depth discussion with the Front, granting a lifetime pension to children with SCZV. At first, the NFRPCZVS thought that MP No. 894/2019 would bring benefits to families, but after careful reading, they realized the structural flaws in the MP that included the nomenclature microcephaly instead of SCZV,

linked receipt of the pension to the previous grant from the CPB, and restricted the pension only to children born between 1/1/2015 and 12/31/2018 (Matos; Silva, 2020b). As a result, the Front, on September 7, 2019, published an official note informing that the MP was “[...] restrictive and unfair, as it did not ensure universal access for children affected by SCZV”.⁷

After great mobilization with researchers and lawyers, the Front, together with some parliamentarians, created new amendments to Provisional Measure nº 894/2019, with the aim of making it more comprehensive. After the installation of PM nº 894/2019, more than 144 amendments were proposed by deputies and senators from the most varied parties, and in October 2019 public hearings began. On April 7, 2020, the Pm was sanctioned and became Law No. 13,985. Although political discussion and mobilization was quite active, few changes were made. Among them are the inclusion of salary and maternity leave for mothers of children born until December 31, 2019, the inclusion of children born in 2019 with SCZV in the pension and the change in the nomenclature from microcephaly to SCZV (Matos; Silva, 2020b).

With the enactment of Law No. 13,985, several families migrated from the CPB to the pension, although many others, who were never able to join the CPB due to the cut of 1/4 of the minimum wage, remain unassisted. This demonstrates that the pension violates the constitutional principle of equality when it links the granting of the pension to those born until 2019 and only to children who are already beneficiaries of the CPB.

Once the law was sanctioned, there was an emptying of the National Front group, due to divergences of interests. For a brief period, decision-making was being done locally. But in 2023, with the change in the federal government, the presidents of the state associations created a new national front. Now called UniZika, this group maintains the purpose of the previous one, which is to mobilize discussions and various federal initiatives, highlighting the discussion on reformulating and expanding the beneficiaries of Law No. 13,985, of April 7, 2020, which granted a pension compensation for children with SCZV.

The associations of SCZV and COVID-19: new challenges

In November 2016, the WHO declared the end of ESPII in zika, and with the reduction in SCZV notifications, in July 2017, the Brazilian Ministry of Health

declared the end of ESPIN and the deactivation of the Public Health Emergency Operations Center (COES), based on the International Health Regulations (IHR). Greene and Vargha (2020) argue that the history of epidemic outcomes has taken many forms and in only a few cases has resulted in the elimination of the disease. This is the example of SCZV, that despite the decrease in cases, children with SCZV continued to be born after the end of the emergency.⁸ However, there is a difference in perception among some technicians, researchers and families affected by SCZV.

For some technicians and researchers, the end of the Zika emergency responded to the IHR's closure requirements.⁹ For the affected families and especially for women/caregivers, everything is still an emergency. Their children still need the same things that were necessary at the time of the emergency, but now without the legal/administrative approval of an extraordinary event such as an ESPII and ESPIN. Greene and Vargha (2020) argue that, in most cases, the end of epidemics becomes a collective erasure, remaining just someone else's problem, that is, the affected children and families. In this sense, although the Zika emergency has been dropped from the agenda, these women and children experience in their daily lives an eternal emergency deepened by the COVID-19 pandemic (Matos; Silva, 2020a).

These women, who already had a history of vulnerability, were impacted in 2016 by the Zika ESPIN and in less than five years they find themselves, together with their children, having to survive yet another emergency, COVID-19, demonstrating that the narrative that “we are all united by contagion” does not hold true when we observe that global epidemics are experienced from local contexts, materialities and situated practices (Segata, 2020).

Such questions reinforce the notion that neoliberalism makes the most vulnerable layers vulnerable globally in the face of epidemic shocks (Nunes, 2020), bringing to light its inability to promote the basics of the most vulnerable layers (Davis, 2020) and that the COVID-19 pandemic intensifies precariousness existing (Butler, 2020), spreading, getting sick and killing unequally along lines of age, class, race, gender and geography (Biehl; Günay, 2020).

Like women who have children with SCZV, the COVID-19 pandemic has deepened inequalities, bringing unmeasurable effects. With social isolation, an entire network of therapeutic itineraries was broken. Based on reports and conversations via WhatsApp, Silvana Matos built an overview of the situations experienced by these women during the COVID-19 pandemic that informs about:

(1) the dissatisfaction of people with disabilities not being included as a risk group; (2) fear of contamination of children and their caregivers; (3) maternal exhaustion and overload as a consequence of the increase in childcare tasks and domestic life, since other children are not going to school, and grandmothers or older women are unable to increase care because they are part of the risk group; (4) rehabilitation therapies interrupted and mothers having to perform complex respiratory physiotherapy maneuvers on their children; (5) interrupted appointments and surgeries; (6) difficulty accessing medication (constant seizures in children); (7) domestic violence; (8) suicide attempts suspended consultations with psychiatrists and psychologists; (9) donation network for basic food baskets and hanging diapers; (10) moral harassment so that they continue to work or fall from work (Matos, 2020).

It is recognized that disability is associated with higher rates of multidimensional poverty (Mitra; Posarac; Vick, 2013), which extends to entire families and has a particular impact on mothers (UNICEF, 2007; 2013). Although the impacts have not yet been measured, the threats of COVID-19, in addition to those already existing for families with members with disabilities, have worsened precariousness and gender inequalities.

Although people with disabilities have been recognized as one of the groups most affected by COVID-19 (UNDESA, 2020; WHO, 2020), the Brazilian government did little to protect and assist children and families during this period. Only on July 6, 2020, the Federal Government launched a plan aimed at people with disabilities and covid – a plan that did not bring anything new and that activists were already putting into practice without federal help.¹⁰ A review of national responses to COVID-19 in terms of disability inclusion in Latin America establishes a link between the region's history of neoliberalism and the approaches adopted by governments. They highlight that the Brazilian government's approach to the protection of people with disabilities is based on individual responsibility, without recognition of additional costs associated with disability in the acquisition of safety equipment and difficulties in accessing usual support (Skellariou; Malfitano; Rotarou, 2020).

The Brazilian government's individual responsibility approach to the protection of people with disabilities conflicts with the human rights approach adopted in the Convention on the Rights of Persons with Disabilities (CRPD), ratified in 2008. Articles 11 and 25 of the convention, respectively, underline the obligation of States Parties to provide protection and security during emergencies and guarantee “the highest possible standard of health”.¹¹ In contrast, the government's “individual responsibility” approach means that the burden of protecting children with SCZV falls to their families and, most importantly, their mothers.

The repositioning of associations seeks to mitigate the weight of "individual responsibility" through collective actions. This was illustrated by the associations' response during the pandemic, in organizing the collection and distribution of "mutual aid", and in providing food parcels and items such as disinfectant and masks, filling the gap left by government inaction. Interestingly, this "individual responsibility" approach to protection and care was also seen during the Zika epidemic in government and Ministry of Health responses, which led to a disproportionate burden on women (Matta; Nogueira; Nascimento, 2019; Porto; Costa, 2017).

Such a scenario highlights the relationship between the government's failure to assume responsibility for protection and care during the Zika epidemic and the COVID-19 pandemic, which has contributed to a double impact on families, whereby the negative and complex intersections of disability, care, gender, social class and ethnicity are exacerbated.

Final considerations

Epidemics highlight the importance of the State and public policies in producing responses for the population. They highlight the important action of the media, social movements and media. In the case of the Zika virus epidemic, what stands out is the capacity for organization, solidarity and activism of mothers who form civil associations. And also, participation in the creation of public policies aimed at promoting the health and social well-being of their children. Over time, these agendas expanded to discussions of class, race, disability and gender inequalities. The ability to dialogue with different instances of power and knowledge production stands out, as well as the use of social networks to communicate with society and highlight its needs, signaling that the epidemic is not over, nor are its effects. In the COVID-19 pandemic, the importance of associations is (re)highlighted. We see that the actions of associations during the pandemic in the search for rights were fundamental.

We highlight the engagement of these women for representation in political spheres. By placing their bodies and voices within associations, on social media, in scientific and political spaces, they leave a condition of invisibility and position themselves as a political force that represents a collective of forgotten voices and needs. In this movement, they are catapulted into parliamentary disputes and aim to occupy municipal legislative positions, as part of the struggle.

Seeking to implement the motto “Nothing about us without us”,¹² some women who have children with the SCZV ran as candidates for councilors in the 2020 elections. In Pernambuco, Germana Soares, who founded the União de Mães de Anjos (UMA), ran the municipal elections in Recife in the first collective list of women candidates for councilors in Recife-PE. Called “Inclusive Councilors”, the ticket is made up of four women: Carol Aleixo, founder of Grupo Super Mães, which fights for the rights of people with autism in Pernambuco; Cibele Albuquerque, person with a disability; and Terezinha Nunes, who created the Parliamentary Front for People with Disabilities in Pernambuco. In Mato Grosso, Fernanda Silva, founder of the association Mães Unidas pelo Amor, was a candidate for councilor in Cuiabá with the motto “fight like a mother”. In Minas Gerais (MG), Vanessa Aguiar, who is part of the Anjos de Minas association, ran for councilor in the city of Lagoa Santa (MG) and Cássia Araújo, mother of a child with SCZV from Bahia, in Salvador with the motto “Woman, Black, Atypical Mother and from the Periphery”.

Despite the beautiful campaign they developed, none of them were elected. For Germana, in a video made available on the official profile of the “Inclusivas” group, this result does not represent a defeat; on the contrary, it reinforces the importance of continuing the fight for the rights of people with disabilities and building a new, more just, humane and egalitarian future.¹³

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Notes

¹ Project “Women’s social movements and the response to Zika”, supported by the Newton Fund.

² This was the last statistic produced by the Ministry of Health, which reveals the negligence towards people affected by the Zika virus epidemic and the government’s understanding of the end of the epidemic.

³ The video showing the letter to Medtrop sent by Germana, president of UMA is available at: <https://fb.watch/ISnXZEzRZD/>

⁴ On this event, see: <https://sbmt.org.br/nota-da-sociedade-brasileira-de-medicina-tropical-sobre-manifestacao-da-uniao-de-maes-de-anjos-uma-no-seu-54o-congresso-medtrop2018/>

⁵ Senate Bill No. 452/2017, authored by Senator Lindbergh Farias (PT/RJ): “Creates a special pension for those affected by microcephaly caused by the Zika virus whose transmission vector is the *Aedes aegypti* mosquito.” See: <https://www25.senado.leg.br/web/atividade/materias/-/materia/131664> Access on: 31 July 2020.

⁶ See: <https://legis.senado.leg.br/sdleg-getter/documento?dm=7873979&ts=1593909218700&disposition=inline> Access on: 31 Jul. 2020. Free translation.

⁷ See Oficial Noe of FNDPSCZV at: <https://www.facebook.com/517099921973951/posts/940784989605440/> Access on: 02 June 2020. Free translation.

⁸ According to Technical Report – No. 01/2020, from the Executive Secretariat for Health Surveillance of the State of Pernambuco, two children with SCZV were born in 2018 and three in 2019. Available at: https://12ad4c92-89c7-4218-9e11-0ee136fa4b92.filesusr.com/ugd/3293a8_596ce18c953340b68ad801efdbdd401.pdf Access on: 25 Oct. 2020.

⁹ International Health Regulations consider the following aspects for the purpose of emergency: (i) the impact of the event on public health; (ii) whether the event is unusual or unexpected; (iii) whether there is a significant risk of international spread; and (iv) whether there is a significant risk of restrictions on international trade or travel. See: <https://www.gov.br/anvisa/pt-br/assuntos/paf/regulamento-sanitario-internacional/arquivos/7179json-file-1> Access on: 25 Oct. 2020.

¹⁰ Available at: https://brasil.estadao.com.br/blogs/vencer-limites/governo-lanca-plano-para-pessoas-com-deficiencia-na-pandemia/?utm_source=estadao%3Afacebook&utm_medium=link

¹¹ According to article 11 of the CRPD: “States Parties shall adopt, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and security of persons with disabilities in risk situations [...]”. Article 25 on Health: “States Parties recognize that persons with disabilities have the right to the enjoyment of the highest possible standard of health, without discrimination on the basis of disability.”

¹² As Pedro Lopes (2019, p. 5) exemplifies, “South African activism for the rights of people with disabilities was established through the fight against apartheid and its constitutive violence”. In this sense, the motto “nada sobre nós sem nós” booms with the struggle of people with disabilities in South Africa (Rowland, 2004; Sasaki, 2007; Lopes, 2019). In 1984, the organization DPSA (Disabled People South Africa) was founded in South Africa, which adopted this motto in 1986. According to Romeu Sasaki (2007), this is the oldest record of the motto “Nothing about us without us”. In 1998, this motto gained new strength, with the publication of the book *Nothing about us without us: Disability oppression and empowerment*, by James Charlton (1998) and in 2004 the book by Willian Rowland (2004) was published, called *Nothing about us without us: inside the disability rights movement of South Africa*. In addition to these initiatives, in October 2018, the UN committee on people with disabilities published new legal guidance, stating the importance of the motto “Nothing about us without us” for this community, and in its general comment reminded that when people with disabilities are consulted, this leads to laws, policies and programs that contribute to more inclusive societies and environments. In this sense, the UN Committee on the Rights of Persons with Disabilities informs that people with disabilities and their representative organizations must participate in decision-making processes regarding their own human rights (CRPD, 2018) (Matos; Silva, 2020b, p. 135).

¹³ P. A. Valente: coordinated the text structure, data analysis and writing. M. N. Antunes: writing, data analysis and standardization of the text. S. S. de Matos: data analysis and writing. L. Avery: writing, production, analysis and mapping of associations. D. N. Pimenta: conceived the research, participated in the analysis and final review of the text.

Resumo

Associações de mães e familiares afetados pela síndrome congênita de Zika vírus: perfil e principais discussões relacionadas

No Brasil, o impacto de emergências sanitárias consecutivas nos últimos cinco anos, como a epidemia de zika (2015) e a pandemia de COVID-19 (2020), atingiu de forma aguda as famílias de crianças com síndrome congênita do zika (SCZ). Este artigo explora processos epidêmicos que replicam as intersecções de deficiência, cuidado, gênero, classe e raça, e propõe a construção de um perfil das associações civis de mães e familiares de crianças com SCZ, bem como suas mobilizações, sobretudo da União Mães de Anjos (UMA). A partir da literatura sobre o tema, realização de entrevistas e oficinas com as mães de crianças com SCZ ligadas às associações em diferentes partes do Brasil, observou-se que as epidemias produzem impactos desiguais em relação a idade, raça, classe, gênero, localidade e deficiência. Embora os impactos das emergências de saúde possam ser contínuos para as pessoas que vivem na intersecção de múltiplas opressões, destacamos a resistência na forma de capacidade organizacional para navegar no acesso a direitos e reconfigurar dinâmicas de poder.

► **Palavras-chave:** Síndrome congênita de Zika vírus. Covid-19. Associações de mães. Brasil.

