

# *The end of unfinished health emergencies* and the Congenital Zika Syndrome

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**Abstract:** Understanding health problems as always unfinished, this article examines consequences of the declaration of the end of a health emergency on the practice of different and interconnected care networks. As part of the “Action Ethnography on Care...” research project, this is a qualitative case study of three documents produced after the announcement of the end of the Congenital Zika Virus Syndrome epidemic. It shows the contexts of narrative production involving researchers, managers/ public service workers, mothers and families of the ill, and mothers’ associations and their different perspectives about what care is. Analyses of a presentation for researchers and of a working paper for the Applied Economics Research Institute (IPEA) question the technical narrative celebrating the end of the emergency based on knowledge and health service without taking into account the relational, affective and political care (of mothers, families and associations), leaving the latter invisible. It describes the process of elaboration of a motion by the Zika Pandemic Forum, listing and systematizing action proposals produced in an explicit dialogue among participants in different care networks to approach unfinished post-emergency questions. It suggests that similar practices of dialogue between networks can promote greater inclusion and sensitivity to care that contribute to reducing suffering and defending the rights of people who continue to live daily with a syndrome or disease whose consequences persist.

► **Keywords:** Zika congenital syndrome. End of health emergencies. Narratives of success and suffering. Care networks.

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## Introduction

This work investigates the consequences of declaring the end of a health emergency on the practices of different care networks, interconnected in an epidemic context. A study of three documents produced after the announcement of the end of the congenital Zika virus syndrome (CSZV) epidemic deals with two questions: 1) their production contexts and the different domains of care highlighted in them; and 2) the differences in the tension of suffering and its relief between networks that operate different understandings of what care is. With this case study, the well-known adage “the epidemic ended, but the disease did not” gains not only a perspective that illuminates the power relations that surround different care practices, but also an agenda to defend the people who continue to live together daily with a disease whose consequences persist.

The SCZV health emergency of national interest, declared by the Brazilian Ministry of Health, lasted 18 months, from November 2015 to May 2017. The emergency of international interest declared by the World Health Organization was even shorter. It lasted nine months, from February to December 2016. It became another endemic among many. The mobilization of “national and international interests” gave enormous visibility to the quality and intensity of dedication and articulation of a response by different agents (mainly researchers, health professionals and related services, families with affected babies and associations). The epidemic with complex and unknown symptoms seriously and permanently affected child development and the lives around these affected people. The response to the declaration led to investments, networks and investigations that achieved rapid scientific discoveries about a previously unknown syndrome. This response to the declaration resulted in unforeseen actions, often praised, that articulated the Unified Health System (SUS) with a diversity of actors to provide care, sensitive to the needs of the affected population and the health care system. It also mobilized thousands of women and families in the exhaustive care of babies and children affected by SCZV. It encouraged the formation and growth of associations and pressure groups to demand and directly contribute to the effectiveness of policies aimed at meeting the needs of those who needed them. It was a frenzy of suffering full of positive aspects.

The SCZV emergency ended more than two years before the arrival of the overwhelming Covid-19 pandemic, and in early 2020, a new emergency of

international concern was declared. Those who were most directly involved in addressing the impacts of SCZV, even after the announcement of the end of its priority, now faced the official declaration of another threat that constituted new official and mobilizing emergency priorities. Those who announce the end of an emergency often perceive their announcement as a victory against adversity. An announcement that they took care of their part. However, this victory takes on the appearance of a defeat, or at least a challenge, by others involved, who continue to care for the people affected, but who lose the political leverage to argue priority and act in a relative consensus about their continued importance. Everyone finds themselves in a new routine that invites an intensification of competition over new prioritizations and meanings around suffering and relief with their care practices.

The dispute emerges between employees whose practices move different domains of care. It often takes the form of a dispute between the technical and the scientific, on the one hand, and the domestic, on the other (Diniz, 2016; Marques *et al.*, 2021; Scott 2020a). It is a dispute in a common field, shared in the desire to alleviate the suffering caused by an illness. Multiple channels of communication show that there are divergences about what the scope of success in care would be and how the scope of the existence of suffering affects cooperation and conflict in different moments of dialogue with the participation of actors from different domains of care.

In this work, we recorded part of the processes of redefinition and negotiation of post-emergency priorities by the different actors who take care of the impacts and challenges of the SCZ between collaborative narratives that sometimes point to success, sometimes point to suffering, in an ambiguous and polymorphous dialogue about the relational contents and objectives of care provided by agents in different domains. Initially, we discuss how end-of-epidemic processes are generally contextualized as periods of expectations and vulnerabilities in an always unfinished process of dialogues that reinforce inequalities and creativity. Then we focus on three documents produced due to the “end” of emergencies, highlighting how care networks are associated, and how the interrelations between success and suffering are configured in each context of the production and direction of documents. The “Action Ethnography on Care ...”<sup>1</sup> team had active participation in two of these productions. The first two documents are from March 2018, just under a year after the declaration of the end of the emergency: an opening lecture at the research evaluation event on Zika (in which we participated as researchers), and a text for

discussion by the Institute for Applied Economic Research (IPEA) – prepared by authors from the Institute and made available to the public without direct participation from our team. The third document, from 2021, was co-produced through during our research collaboration.

Reading the two documents from 2018, with a qualitative approach that combined ethnography with participation in events and document analysis, aimed to identify which actions were highlighted, how the narratives of the authors/presenters evaluated the actions taken to combat the epidemic, and the attribution of initiatives and creation of results deemed relevant by the authors. These observations were associated with the emphasis and absences of the narrative about knowledge, care, affection and politics to understand different perspectives on “how, with whom and what is taken care of” in the epidemic and after it. The 2021 document was already organized by the objectives that guided the research team to promote dialogue between managers, professionals, mothers and associations. The procedures are detailed later in this text. The in-depth examination and presentation of information about the specific case of SCZV is already one of the concrete contributions for everyone who is interested in it. The discussion about the understanding and practices of different care networks in the context of emergencies contributes to debates that can help to understand important processes in responses to epidemics in general, favoring practices of inclusion and dialogue that recognize the diversity of perspectives, the importance of mutual understanding, defense of rights and the reduction of vulnerabilities and suffering.

The first of the documents analyzed is the presentation organized by the National Network of Specialists in Zika and Related Diseases (RENEZIKA) at the opening of the Second Assessment Seminar for seventy people responsible for projects underway in Public Call no. 14/2016 (Prevention and Combat of the Zika Virus). Its purpose was to guide the debate between researchers, specialized coordinators for working groups and technicians from the National Council for Scientific and Technological Development (CNPq), the Coordination for the Improvement of Higher Education Personnel (CAPES), and the Department of Science and Technology of the Ministry of Health (DECIT-MH). The meeting took place in Brasília, in March 2018. It was followed by other evaluation meetings until December 2021. The lecture slides were presented nine months after the end of the national emergency, to update people

committed to continuing their research and management efforts to take care of the response to the syndrome, since the research had a defined period of four years.

The other document examined was produced at the same time as the Zika emergency ended. It is an assessment of the situation: a characterization of the “confrontation” done by Letícia Garcia (2018), from IPEA, published to discuss its scope and implications.

The third document was produced in another historical period, when the new emergency had already been declared and the population was facing a long quarantine. The end of the international Covid-19 pandemic was approaching, but it was still undefined, and the general alert was on for any sign of a resurgence that would lead to an extension of the emergency. The document is a motion produced by the “Fórum Zika na Pandemia em Pernambuco”, in September 2021, as part of the IV National Meeting of Anthropology of Health (IV RAS), with the coordination of our research team, to make visible the demands existing in the promising period of the oscillating and doubtful<sup>2</sup> approach to the official national closure of the Covid-19 pandemic emergency, formalized on April 22, 2022. The declaration of the end of the international emergency occurred after many deliberations, only on March 5, 2023.<sup>3</sup>

National emergency exits bring balances of narratives of success and continued suffering. They present challenges fueled by the consequent widespread demobilization of control and surveillance mechanisms for some Zika care. In the second period, as the end of the Covid-19 emergency approached, the discussion available on the Social Sciences and Zika Network<sup>4</sup> shows that researchers already understood that the Zika epidemic was becoming a neglected disease. The Forum document was produced in a creative and purposeful dialogue between different caregivers, stakeholders in the effort to make ongoing needs visible, using narratives of success, suffering and challenges that reflect and result in practices of cooperation and competition of different actors in different domains in the process always unfinished of taking care of Zika.

## Care entangled in epidemics that (do not) end

An epidemic always authorizes many governance actions, placing them in priority (Silva *et al.*, 2017) and mixing narratives of success, commitment and suffering.

From local to international levels, it combines war narratives with humanized and caring ones, to combat the harmful effects and images of the epidemic. Fassin (2012) makes a good characterization of the calls to action in humanitarian situations that perpetuate unequal power networks, even when they appear to be alleviating such inequalities. The author understands that moral feelings lead to a concern for the suffering of others and points out that compassion when directed towards others usually occurs in a context of distance and incomplete dialogues that favor governance, regulating and managing the existence of these other human beings. Actions that are highly motivated to alleviate suffering from the most diverse origins are also strongly influenced by notions of acuteness that lead to a temporal circumscription that favors a search for recognition that they have caused relief and can be ended or at least clearly reduced.

The narrative of the people most directly affected comes from the deleterious impacts on their daily means and places of living (Escobar, 2008), which require their own daily care even when they also require specialized support to alleviate suffering. As Duarte and Leal (1998) observe, the suffering experienced and narrated gives social value to the dedication of the people who suffer. The suffering of a caregiver, even when it physically isolates them from many others, in practice evokes an insistence on relationality as an element that values them. This easily becomes a new phase of demanding activity, both individual and collective. Such a disposition can result in political creativity that makes the voice, simultaneously domestic and collective, evidence of an affective and relational side that calls for inclusion in considerations on how to take care of its impacts in a horizontal and sensitive way.<sup>5</sup> Suffering itself, and the search for its relief, favor the emergence of biosociality and bioidentity activism groups (Rabinow, 1996; Rose, 2012), which combine domesticity, affection, care and relief with the continuity and permanent adaptation of care and knowledge, and not with the announcement of any end to the urgency of caring. Generally, these groups of associates are led by people who live directly with those affected by the disease.

The metaphor of war that accompanies “the fight against epidemics” produces heroic and suffering narratives multifaceted by bravery and selflessness, by the defense of populations, by the delineation of social and territorial borders, by the exhausting times of dedication to care, by the intensity of feelings, as well as the importance of the accelerated speed of time as a measure of effectiveness. The narratives of success

and suffering produce inequalities, at the same time that they stimulate creativity and stamp various actions related to care as worthy ideas in the lives of groups mobilized to take care of whatever is necessary during an epidemic and after it.

The Zika epidemic, with its particularities, but similar to other epidemics, presented important challenges, including understanding the syndrome itself, adapting the care system to new demands, creating conditions to support the daily lives of mothers and families of those affected, adjusting the rights to care and reviewing responsibilities, and knowing how to listen to and appreciate the multiple experiences of people's perspectives (Marques *et al.*, 2021; Fleischer; Lima, 2020; Scott; Lira, 2020; Scott *et al.*, 2018).

The activation of the National Network of Specialists in Zika and Related Diseases (RENEZIKA) and the publication of a multidisciplinary and multisectoral notice to combat Zika are two comprehensive examples, among thousands of efforts to combat it in spaces of preventive, combative and also affective surveillance. In Garcia's (2018) detailed report, produced at the end of the epidemic, the incredible sequences of protocols, alerts, decrees, action plans, guidelines, technical notes, ordinances, regulations, committees, mandatory records, notifications, situation conference rooms, promotion of events, monitoring, budget releases, funding searches, guidance, calls, mobilizations, awareness raising in schools, formation of dissemination networks, etc. that populated the fight against the epidemic.

The environment of priority among priorities contaminated all domains of care related to the new syndrome, which include domains of: a) relational care, of mothers and families with their affection and attention to the health of children and babies born with microcephaly and other symptoms related to the Zika virus; b) health care, from the health system that reorganizes its services to make space for assistance and treatment; c) care for comprehension, through researchers who investigate the knowledge and etiology of the disease; and d) political care, from associations that act politically, administratively and judicially to ensure that support reaches those who live with the disease on a daily basis. Each element in this multifaceted set of care networks makes up, simultaneously, a separate particular domain and a domain intersected with the others, closely entangled as care mixing the technical and the human at the same time. In practice, without losing their explanatory value, the ontological, genealogical and critical aspects of care that Ayres describes become barely separable (2004). They also highlight the construction of people within

different power relations frameworks (Bustamante; McCallum, 2011). It is a tense network with unequal narratives in the common response to the emergency.<sup>6</sup>

Somewhat laconically, even though there is a multitude of specific technical directives, in its guidelines, the National Health Foundation of the Ministry of Health glosses over details and declares that the exit from an emergency depends on “strengthening municipal epidemiological surveillance systems, endowed with technical-managerial autonomy to focus on health problems specific to their respective areas of coverage” (MH-Funasa, 2004, p. 12).

This technical capacity associated with “areas of coverage” assumes expected outcomes – actions that require confidence that there will be sufficient continuity of processes being implemented to achieve responses, even after the epidemic has ended. In terms of care network domains: the comprehensive care network would ensure that understanding the etiology and characteristics of the pathology would be sufficient to prevent and remedy it and restrict its expansion; the care network would ensure that the health system would have spaces for treatment and rehabilitation of affected people; the relational care network would bring together humanized and integral affectivity and sensibilities of the system with the responses of people socially close to the affected people to enable the daily experience of caring; and the policy care network would articulate the demands and effectively reach the necessary support for the affected people, monitoring, executing and identifying demands and rights.

From the perspective of João Biehl (2020), social processes, and specifically health and illness processes, are always unfinished. The announcement of the end of an emergency is presumed to be an announcement of a new escalation of priorities when dealing with an epidemic disease, and not simply an end. It is a reordering of care networks that simultaneously accentuates successes and vulnerabilities built by people related and associated with their irremediably mixed areas of technical and everyday coverage.

Anyone looking at the end of the Zika epidemic points out a series of achievements, successful or not, suffering or not, from the angle of some aspect of care, and also points out many concerns about the implications for people's lives and creativity, building their projects in dialogue with others in these announced and unfinished processes.

## Is the SCZV emergency over: successful technical narratives?

At the beginning of March 2018, the researchers from the national research call 14, invited to the CNPq headquarters to discuss their research funded in eight thematic lines, arrived in Brasília. They were instructed to attend the opening lecture of the Assessment Seminar. The lecture preceded three days of rich thematic debates in four working groups<sup>7</sup> to discuss, thematically, each specific effort to understand and care for Zika and its effects. The presentation with 34 slides, written by RENEZIKA, was titled “Dengue, chikungunya and zika: plan to combat *Aedes* and its consequences”. Well updated, the data reference cutoff date was February 17, 2018 (two weeks before the meeting).

It was a self-congratulatory show of precious information designed to spread positivity among researchers about the construction of knowledge and among managers about the organization of prevention, combat and training services for care. After reporting on the formal “birth” of the RENEZIKA network and the timeline of public responses, it presents the dimensions of transversality and development of partnerships between institutions and countries that coordinate the work, identifying three main axes of action. Two of the three organizational axes of the informed network received explicit treatment throughout the presentation: *mobilization and combat against the vector* and *technological development, education and research*, leaving the less quantifiable axis, *care*, without an explicit approach, being understood, perhaps, that everything was, in some way, care, it is not appropriate at this time to talk about relational affection or rights.

To face the enemy, the mosquito vector, identified in the “mosquitocentric” title as the main target of attention, 82 million reais were invested in larvicides (Piriproxyfen and Melation) and application equipment, another undefined high amount for 404 vapor spreading vehicles, surveillance on the presence of mosquitoes in the entire universe of the nation's municipalities, and school education on mosquito outbreaks in 188 municipal and 103 federal schools (universities and technical institutes). Regarding technology, education and research, there is information about an even higher investment: over 872 million reais for rehabilitation centers throughout the country, provision of new professionals in therapeutic areas, training with annual continuity at high prices, in addition to expenses not reported for some workshops and guidance publications for professionals, families and primary care support

teams. Recognizing the need to help families deal with the consequences of SCZV, an emphasis on early stimulation, ocular therapy and “play therapies” is identified as part of priorities for the care of Zika and STORCH<sup>8</sup> pathogens in general. The results of these actions point to the trends up to February 17, 2018: 3,817 confirmed cases with technical rigor in collection and investigation and an intense decline in cases. The final slides show that from 2016 to 2017, all diseases caused by mosquitoes fell: 33% for chikungunya, 83% for dengue and 92% for zika. A positivity packaged by the words in the first part of the presentation:

WHO recognizes RENEZIKA as an example of a rapid and effective response to combat Zika: At a meeting in London to discuss combating public health emergencies, RENEZIKA was highlighted for contributing to scientific and technological advances. The way Brazil is dealing with the fight against *Aedes* has sparked international interest in investments and the formation of partnerships with Brazilian research institutions (Source: Presentation II Evaluation Seminar, free translation))

The heroic justification of internationally recognized success with so many details and high figures of the collective effort spent on knowledge and service care supports a search for agreement that the epidemic is over and that the research that continues to be discussed in the 2<sup>nd</sup> Evaluation Seminar will continue being contributions to the fruitful Brazilian response to the epidemic after the emergency. Explicit reference to suffering or actions to claim rights is completely absent.

In the same month of February 2018, in another technical context (IPEA), the discussion text “Zika Virus Epidemic and Microcephaly in Brazil: Emergency, Evolution and Confrontation” was published by Garcia (2018), written with the greater acuity that an extensive text allows. The document contributes additional perspectives of technical guidance for policies and actions. It catalogs the many actions that this text presents. In a careful technical narrative and with a more measured positivity than the lecture presentation discussed above, it goes through the trajectory of the disease and the administrative formalizations and disciplinary organization of coping, confronting, and reporting causal definitions and the complexities of manifestations. At the same time, it assumes the production of a narrative of success in many places in the text, highlighting the nominal details of actors, the efficiency and the scope of the organization of Brazilian health surveillance. It contributes to the “great scientific event” and to the international recognition received from Margareth Chan, director of the WHO, who said that “I had never seen such strong involvement, such strong leadership from a president

towards a problem like this, both in relation to the speed of their actions and the seriousness and level of involvement” (Garcia 2018, p. 16).

The heroic success assumed by the combat network was enhanced by scientific discoveries ranging from the causality between “a rare exposure – Zika virus – and a rare congenital defect – microcephaly” (Garcia 2018, p. 23-24) to several other subsequent discoveries. This international recognition is reiterated in the final documentation:

It should be noted that the Brazilian response to the Zika virus epidemic was praised by representatives of the WHO and PAHO, who highlighted the country's transparency in sharing data and protocols, which allowed the transfer of knowledge to other countries (Garcia, 2018, p. 38).

At the end of the text, Garcia takes on a more reflective tone, taking five pages to open up the challenges and point out what is unfinished. The last pages are called “Current and future challenges for the prevention and control of Zika virus fever and its consequences in Brazil”. First, it enumerates the challenges:

[...] those related to care for children with microcephaly and their families, reproductive health, gaps in biological, clinical and epidemiological knowledge regarding Zika virus infection and its complications, research and development of vaccines and laboratory tests, in addition to improving and developing new strategies for controlling *Aedes aegypti* (Garcia 2018, p. 38).

The first two items on the list are broken down into demands for intense care from families of young, black and poor women who live in vulnerable areas. In addition to indirectly valuing mothers' experience and suggesting rights arising from their vulnerabilities and suffering, the text insists that, even though the SUS has an important role in ensuring citizens' rights, mothers (and their partners) are poorly served regarding reproductive health. To detail rights, it refers to the recommendations of the Gender and Health Group of the Brazilian Association of Public Health (ABRASCO), mentioning the lack of action regarding the confirmation of the sexual transmission of the pathology, in an action that simultaneously disciplines and potentially empowers women. Following its characteristic as a discussion document on economics (after all, it is the policy-centered IPEA – Institute for Applied Economics), these issues that cause dilemmas for families who live with the consequences of the syndrome, even when recognized, are not explored in depth.

The text addresses more carefully the costs involved for the State and the economy in the form of dropouts and absences from work and drops in productivity – which “cruelly” affects families and makes the economy suffer as well. The approach

makes it possible to indirectly visualize relational dilemmas, as well as welfare, humanitarian care and social security, recognizing actions from other government sectors, such as transportation (for those who live far from service locations), housing (priority in participation in the *Minha Casa Minha Vida*), welfare for the poorest (Continuous Payment Benefit – BPC) and sanitation (to eliminate mosquitoes and contribute to healthy living environments).

The final part of the text recognizes the unfinished and appeals to the relationship between differentiated domains of care in people's own governance, objectifying them as a suffering population deserving of care actions. Suggestions for action from various sectors of the government leave completely silent the possibility of creative collaboration by these people who adapt responses and demand policies to alleviate the impacts of SCZV on their daily lives. In addition to identifying some challenges of scientific issues (clear diagnoses, vaccines, other transmitting vectors) and care that have not yet been resolved with insensitive bureaucracies and access difficulties, it has the sensitivity to refer to relational, social and rights dimensions that need attention, even without referring to information coming directly from these caregivers. Interestingly, the text says nothing about the associations that fight for the living conditions, sociability and rights of these families, who at that time were very publicly active in distributing information, donations and demands, united in a National Defense Front created in 2017, when the end of the emergency was announced (Matos; Silva 2019, 2020; Scott, 2020b, 2021; Moreira *et al.*, 2018).

The policy of visibility and inclusion of mothers and associations in what should be considered as care was very well highlighted when an association of mothers, touched by exclusionary forgetfulness, challenged researchers and managers in the field of Tropical Medicine, at its Congress in September 2018, including their participation, associations, as the voice of mothers, in the simultaneous meeting of them and RENEZIKA, well documented by Matos e Silva (2020) from the “Action Ethnography on Care” research team in the work “Nothing about us, without us”.

## “The Covid-19 pandemic will end”: a Forum on care for the unfinished Zika epidemic

With the loss of priority status caused by the declaration of the end of the SCZV epidemic, resources for research and care had been dwindling. The affected

babies, each developing within their capabilities, had care provided by mothers, families and associations, who sought to show and fight to satisfy the need for continued care, support and knowledge sensitive to the changes they were going through. Most of these caregivers maintained an acute awareness of their dedication as an ambiguous combination of suffering and an affective relational commitment expressed in repeated and varied gestures of maternal and familial attachment. Less and less research and service spaces were dedicated to solving the problems of responding to the epidemic, which was praised as being efficient and generating knowledge shared nationally and internationally. The increasing difficulties in receiving care and discovering new knowledge to solve problems that have arisen have called into question the condition that FUNASA had announced to emerge from a health emergency: “technical-managerial autonomy to focus on the health problems specific to their respective areas of scope” (Brasil, 2004, p. 12). History has reserved a much more striking accentuation of this process of “invisibilization.”

The Covid-19 pandemic (im)mobilized the world from the beginning of 2020. It had profound consequences for everyone. It could not be different for those affected by SCZV (Grossi; Toniol, 2021). The announcement of its end was highly anticipated in the world and in each nation. Half a year before Brazil announced the end of the pandemic (April 22, 2022), the country still maintained confinements and movement restrictions with an indefinite opening time. Everyone was trying to organize themselves for the new moment.

To encourage attention to the knowledge and demands formulated by actors in different care domains, the “Action Ethnography on Care ” research efforts encouraged the elaboration of the “Motion of the Zika Forum in the Pandemic” approved at the IV Anthropology Health Meeting in Brazil, on September 24 2021, supporting recommended actions to address the impacts of the Zika virus to examine the thematic reconfiguration of the complex connections in the care network, privileging dialogue between representatives of the different care domains affected, both by the end of the SCZV epidemic itself, and by the Covid-19 pandemic.

The motion was a culminating moment (but not finalizing) for the objectives of promotion and production, sought since 2016 in engaged research, of a dialogue to increase sensitivity to experience and knowledge between mothers and families, citizens and State services and researchers related to “Fighting Zika.” Many activities prepared this moment. We highlight:

- daily ethnographic monitoring of therapeutic itineraries between home and services (Scott *et al.*, 2018) and more than 112 recorded interview and other informal ones;
- dialogue with Health Secretariats and associated technical departments;
- organization of events, presentations, production and publication of written works;
- collaborative coexistence with two associations working in favor of mothers of children affected by SCZV;
- holding an audiovisual course with mothers who produced (script, direction and narration) their stories in five videos telling the experience and shown and discussed in key locations<sup>9</sup> and made available on the internet;<sup>10</sup> and
- participation as co-protagonist witnesses in legal decisions (Matos; Silva, 2019; Matos, 2020).

With all this, a multiplicity of communication and dialogue channels had been created that aimed to connect mothers with managers and researchers. Many of these channels had been losing their effectiveness and visibility in the demobilizing context of the pandemic. We responded during the pandemic by increasing training and participation in numerous “social” groups (WhatsApp, Instagram and Facebook) functioning with varying efficiencies in the context of extended quarantine. It was in the second year of the pandemic that the document that became a Motion was created.<sup>11</sup>

We sent the invitation, in June 2021, to a group intentionally chosen for their known commitment to responding to SCZV evidenced in the four years of research up till then: four mothers of children with SCZ, the two directors of associations, five health professionals and managers, and three researchers. Each participant was interviewed virtually on camera by two rapporteurs to transcribe the interviews and, in dialogue with these people, turn the answers into thematic phrases of demands that were part of the text to be discussed together in the pre-event forum, on September 22<sup>nd</sup>. The final wording was presented and approved on September 24<sup>th</sup> as a “Motion” at the assembly of the IV Health Anthropology Meeting, open to more than 500 registrants.

The invitation to supporters to participate in the preparation of the forum document expressed concern about the “eclipse of attention to Zika” and explained two objectives:

- a) recording experience reports on the impacts of Covid-19 in developing responses to the Zika epidemic for the various groups associated with it; and
- b) recommending measures that could contribute to redirecting or resuming actions that were hampered by Covid-19.

They were asked to speak freely about three questions: the changes that the Zika epidemic brought to their activities in the care actions in which they were involved; the changes that the Covid-19 pandemic brought to actions related to Zika, and recommendations on current and future actions in relation to Zika. The first two questions produced contextualizing narratives to clarify the motivations for the recommendations contained in the motion. Members of our research team were participant encouragers who drafted the version of the motion taken for discussion. The version was commented, discussed and amended by 50 people on the Forum. The recommendations that resulted from this process are self-explanatory and contained in the full document attached at the end of this article.

Using the virtual format that confinement required, this entire discussion took place on an equal footing on the screen. Recommendations from researchers, service providers, mothers and associations reflected our understanding that comprehension, assistance and treatment, relational and political networks are discrete but intersecting domains. The thematic analysis of the recommendations allowed us to extract transversal and convergent themes in the narratives of claims for kinds of care. The text was forwarded to relevant associations and institutions and also to each participant so that it could be shared in the way they deemed most effective to support the adaptation of all caregivers to the impacts.

In the same way that Mol (2002, 2008) discusses, it became evident that different practices lead to multiple perceptions to understand a disease and its effects, and this affects how groups from different care domains formulate suggested actions to resume or initiate measures that can rebuild the combat and dedication processes in the SCZV care network.

## Care in the end of emergencies: fewer exclusionary technical successes, more dialogue, sensitivity and rights

From the intersected space of dialogue to formalize the creation of the document of recommendations for actions in the Forum, foreseeing an end to the pandemic,

convergent transversal themes emerge between the different caregivers. It is not just a result of the format and procedures of the approved motion. The common scenario of Covid-19 suffering and neglect changed the previous, more restricted scenario, after the end of the state of emergency in 2017. The new scenario diminished use of success narratives and brought to the surface unfinished and emerging issues in the possible treatment of SCZV in the interest of all caregivers.

The themes of cross-cutting recommendations, formed by combining specific recommendations and characterizing them into more aggregated discrete categories, include:

### **Expanding integrated health services with several others across sectors**

The insufficiency of the services offered became more evident during the pandemic with dismantling and impediments already in progress being accelerated in the name of Covid-19 priority. The expansion should include a diversity of health services, and go beyond the limit of the area, requiring adequate integration with other service sectors, such as education, welfare, transport, housing and sanitation.

### **Adapting services to the rhythms observed in children's development**

Based on the experience of mothers and new information from research and care, therapy is suggested for the psychological and physical suffering of overworked mothers and for delays in the development of children who have had to be absent from therapy. In addition to renewed therapies, there should be expansion that goes beyond early stimulation and attention to the various manifestations of disorders identified during the epidemic, adding more maintenance therapies and palliative care aimed at coexistence, sensitive to the new conditions. Due to age, it should also include more spaces in daycare centers.

### **Joining with other categories and groups to reinforce demands**

It is seen as important not to restrict demands to just Zika, recognizing that inclusion in broader group categories also provides continuity of care to issues of interest to those caring for Zika. As has been done since the beginning, attention to arboviruses in general (zika, chikungunya, dengue and Guillan-Barré) is recommended, as well as the inclusion of more lifelong care in the care of all people with disabilities and rare diseases; and, depending on the demands on mothers

and sexual transmission information, inclusion in reproductive health policies to reinforce conscious decisions by mothers and couples.

### **More sensitivity to comprehensive care and to sharing action/information**

Understanding the individual and the demands for comprehensive health care can help overcome excessive bureaucratization, fragmentation, specialization and overemphasis of creation of data for research. It should be avoided that such excesses lead to impediments of action, withholding of information and exclusion. Actions to enable registration efficiency and especially more open sharing of information with mothers and inclusion of mothers/family members and associations in policy dialogues and decisions add up as sensible responses that can contribute to reducing exclusion.

### **Acting on technically and politically neglected issues**

The recognition of unanswered questions requires continued research and collaboration around the development of vaccines, the discovery of new or intensified means and sequelae of infection, and the dynamics of sexual transmission, as well as requiring more actions and policies on sanitation and promotion of combating inequalities.

### **Paying special attention to moments of acute suffering**

With the high mortality experienced in Covid-19, there was renewed concern about the rates and effects of high mortality in people affected by SCZV, which has received little attention. It is important to see the effects of morbidity and mortality and family recomposition from Zika and Covid-19 on people in home care networks.

In general, the effects of Covid-19 on the complex care network were multiple: therapy centers, UPAs, ICUs and referral centers closed, redirected and dismantled; daycare centers not working, means of transport unavailable, face-to-face care and consultations obviated and replaced by telehealth, isolation at home with demands for care increasing concerns and a drastic reduction in formal and informal work, the stress of confinement that required even more dedication from women to domestic services, associations with fewer donations and unable to promote sociability and aid actions, fewer official and philanthropic donations, research suspended and redirected, children's health weakened with developmental delays due to lack of

physiotherapy and other therapies and concerns about hospitalizations being made impossible or difficult due to the dangers of contagion and priority focused on Covid-19.<sup>12</sup> These are possibilities of knowing, attending, relating and claiming that are being resized in an environment of suffering and limitation of success narratives that act to stir up the negative effects of the end of an epidemic that, finished and unfinished at the same time, redefined the activities of many people.

## Final considerations

The end of the Zika epidemic, in the documents seen in 2018, provoked shared narratives of success, knowledge, management and service with international recognition. Dedication to partnerships and seeking funding for the many research, actions and training required a lot of effort and negotiation, but it was not seen mainly as suffering. It was narrated by researchers, professionals and managers as commitment and articulation. The dedication of mothers to their children, understood as suffering alleviated by actors in these domains of knowledge and care, was experienced by mothers as suffering filled with affection that their relationship with their child required as a caregiver, which often needed to be leveraged into a report of success in participating in a collective struggle for their rights as citizens. This narrative of success, little visible in the documents seen, was reinforced, directly and indirectly, by associations where there were also other mothers in the same situation. The success story of these mothers was being able to turn their dedication into a political weapon so that they could enjoy their rights as citizens with access to adequate knowledge and care for their children. Success, also, in becoming citizens, partially managing not to be relegated only to invisibility or identification as sufferers and managing to create, in their sociability with other active mothers, a positive space for themselves, activating a uniting “bioidentity.” As people who lived and will continue to live daily with children who grow and change their demands, their success pointed to a need to recognize that the growth of their children, health and citizenship demands on their special children would always require a look at an unfinished reality and for the post-epidemic future that would require new fronts of action and new qualities of dedication.

A different perspective opened up with the Covid-19 pandemic. Brazilian technical and political incompetence in responding to the pandemic prevented

successful narratives with delays in the use of vaccines, lack of materials and equipment, recommendations of inappropriate drugs, and mortality figures well above the world average. It led most researchers, managers and professionals to criticize and demand to repair errors. Researchers lost visibility and managers and professionals were much more overloaded. The public success in recognizing health professionals was due to their exposure to suffering and their selflessness and dedication in a very demanding, but poorly operational system. Hopeful gaps for post-pandemic periods appeared and disappeared soon after.

For those who remained in Zika care networks, as on other fronts of action, the expectation of an end to the pandemic led to the possibility of reestablishing a lost order of care. A kind of reconfiguration to reach where all had already arrived, while it required creativity to understand the new demands created by the unforeseeable historical experience in a non-triumphal dialogue, quite reflective and of mutual respect and convergence. The presence of mothers and associations as highly recognized stakeholders is a factor that contributes to a greater environment of exchanges, collaboration and a path towards mutual horizontalization of narratives and recommendations for reducing suffering. The Zika Pandemic Forum was a limited and isolated action with potential for expansion. Above all, it opened spaces for a dialogue between networks that included the relational, affective and political networks of mothers and associations with knowledge and treatment networks. Everyone has a lot to learn from this dialogue interconnecting care networks.

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## Notas

<sup>1</sup> “Etnografando Cuidados e Pensando Políticas de Saúde e Gestão de Serviços para Mulheres e Seus Filhos com Distúrbios Neurológicos Relacionados com Zika em Pernambuco, Brasil”. FAGES (Núcleo de Família, Gênero, Sexualidade e Saúde), Universidade Federal de Pernambuco CAPES (8888.130742/2016-01), CNPq (440411/2016-5), DECIT-MS e “Action Ethnography on Care, Disability and Health Policy and Administration of Public Service for Women and Caretakers of Zika Virus affected Children in Pernambuco, Brazil, FACEPE/Newton Fund (APQ 0553-7.03/16).

<sup>2</sup> See questions at the National Health Council (<http://conselho.saude.gov.br/ultimas-noticias-cns/2446-quem-define-o-fim-da-pandemia-nao-e-o-ministerio-da-saude-e-nenhum-pais-mas-a-oms-diz-pesquisador-em-reuniao-do-cns#:~:text=CNS%2C%20Fernando%20Pigatto.,%E2%80%9CQuem%20define%20o%20fim%20da%20pandemia%20n%C3%A3o%20%C3%A9%20o%20Minist%C3%A9rio,Fiocruz%2C%20Raphael%20Mendon%C3%A7a%20Guimar%C3%A3es>). Access on: Jan 3rd, 2023.

<sup>3</sup> <https://gauchazh.clicrbs.com.br/saude/noticia/2022/10/o-que-falta-para-a-oms-declarar-o-fim-da-emergencia-sanitaria-internacional-da-covid-19-cl9rh7mcf001p01g7lhjyg2db.html> Access on: Jan 3rd, 2023.

<sup>4</sup> <https://fiocruz.tghn.org/zikanetwork/> no vídeo Epidemia do Zika Virus 5 anos depois <https://www.youtube.com/watch?v=nSHsQInytCE&t=693s> Access on: Jan 2nd, 2023.

<sup>5</sup> Bonet e Tavares (2006) discuss interstices and complexities of the networks woven at this level with those of customer service at PSF.

<sup>6</sup> See Scott (2020c) on care domains.

<sup>7</sup> GT 1: diagnosis, immunobiological, immunology, virology; GT 2: Social technologies and innovation, Innovation in service management, epidemiology and surveillance; GT 3: Repellent evaluation, Vector control; GT 4: Pathophysiology and clinic.

<sup>8</sup> The bacterium *Treponema pallidum*, which causes syphilis (S); the protozoan *Toxoplasma gondii*, which causes toxoplasmosis (TO); and rubella virus (R), cytomegalovirus (C), herpes simplex virus (H), together make up the acronym STORCH to refer to pathogens that pose potential risks to the fetus. After the Zika epidemic, it was renamed STORCH+Z.

<sup>9</sup> UFPE, State Secretariat of Health, IPEA, National Scientific Meetings of Social Sciences, Columbia University, Johns Hopkins University, Sussex University.

<sup>10</sup> YouTube (YouTube <https://www.youtube.com/watch?v=6o6UyOx8tqs>, Rede Zika das Ciências Sociais do FIOCRUZ, *Epidemics cluster* da Sussex University).

<sup>11</sup> See Annex 1.

<sup>12</sup> Matos (2021) prepares a list detailing impacts focusing on mothers.

# ANNEX 1

## **MOTION in support of recommended actions to deal with the impacts of the Zika Virus approved in the plenary of the IV Meeting of Health Anthropology on September 24, 2021, disseminating it to decision-making bodies to support their actions.**

Mothers, caregivers, associations, managers and professionals, and researchers with personal experience in dealing with the effects and impacts of Congenital Zika Syndrome, concerned about the eclipse that has been occurring in meeting the demands of this syndrome, after a period of three months of conversations, met on September 22<sup>nd</sup>, Wednesday, from 9:00 to 12:00, before the Fourth Health Anthropology Meeting and deliberated on a set of 59 recommendations for actions to reinforce the effectiveness of attention to the syndrome for that it is adequately treated. The names of those who contributed to the preparation of these recommendations over the three months and who participated in the open debate for the public at the forum Zika in the Pandemic in Pernambuco: Impacts and Possibilities on September 22<sup>nd</sup>, are listed at the end of the document.

The collaboration was coordinated by Parry Scott and Marion Teodósio de Quadros of FAGES – PPGA UFPE with a team of group reporters included in the list of participants at the end of the document.

### **Recommendations for organizing services to meet the demands of Zika**

#### **Mothers**

1. More education, more health, more doctors and advanced therapies.
2. Greater agility in booking appointments and managing therapy centers.
3. Expand care with contacts that can harm caregivers and school meals.
4. Take up again government transportation and improve it.
5. Carry out more health treatments for caregivers who face a lot of anxiety, difficulties, and concerns that need psychologists and psychiatrists.
6. Get more specific therapies to prevent worsening of children's health.

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7. Improve the provision of treatment in the interior to reduce the need for travel.
8. Open training and vacancies especially sensitive to mothers or other caregivers of children with disabilities, and in stable health.
9. Return to previous levels of donations because there was a decrease.
10. Avoid returning to the end of waiting lists for those who needed to be absent from care during the pandemic.
11. Attention to the dangers of transmitting the virus upon the return or insertion of children, their caregivers and other members of the school.
12. Recognize the outstanding commitment of some professionals who made themselves available to families even during the pandemic.
13. More attention to changes in the composition of families throughout the child's development.
14. Widespread inclusion and monitoring of comprehensive health care for mothers and other caregivers.

### Associations

More continuous flow of donations so that UMA can continue with its activities.
2. Public policies aimed at caregivers.
3. Quality rehabilitation.
4. Availability of equipment that children need for their development.
5. More voice for associations in public policies.
6. That managers and researchers can talk more with the associations, because the associations know about the demands and pains of these women, because things are often done without consultation.
7. Give visibility to associations, because we are fragile and invisible.
8. Priority access for mothers and other caregivers to COVID-19 vaccination, as well as children with SCZ, within the approved age group.

### Service providers

Need to rethink the diseases caused by Zika and other rare diseases more broadly.
Improve understanding of the clinical portrait of children with SCZ.
3. Carry out more studies and research, as the Zika virus is a new syndrome and the understanding of its consequences is still incipient.
4. Adapt actions and ensure monitoring of the demands of children with CZS that are constantly changing, beyond early childhood.

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5. Change indicators, taking into account changing needs as children grow. Greater focus on therapeutic maintenance and palliative care, as the emphasis on rehabilitation is not sufficient
6. Train health professionals to qualify and raise awareness of the care and demands of children affected by Zika and to provide qualified listening to mothers.
7. Carry out campaigns and competitions to hire health and education professionals who are sensitive to the demands of children with Congenital Zika Virus Syndrome.
8. Increase teams and spaces, creating new opening hours
9. Continue the expansion and regionalization of the health network given the gaps still present in the provision of services. For example, the provision of orthopedic services such as Risotomy, which is in the process of being implemented.
10. Ensure improvements in medication and food assistance, given that anticonvulsants and nutritional supplements are expensive. Many children do not have access to this support and do not develop properly.
11. Strengthen campaigns and prevention measures, given the recent increase in cases of arboviruses.
12. Stimulate intersectoral coordination between public services to better understand the reality of families affected by the Zika Virus.
13. Train new managers who integrate service networks in order to inform their operation and the historical monitoring of social demands.
14. Keep federal, state and municipal databases updated and available for assistance services.
15. Facilitate the exchange of data from different bases, as each municipal, state, regional and federal sector [in the areas of Health, Education, Social Assistance, etc.] has databases and information collected and made available in a different way.
16. Collection of data necessary for monitoring families by social assistance in each municipality.
17. Inclusion of the NIS and/or CPF of the mother/caregiver/caregiver or child in the Health Departments database.
18. Think about strategies for constructing and making information available that privilege the individual's knowledge as a whole.
19. Greater attention to the sexual and reproductive health of female caregivers and couples.
20. Establishment of a monitoring flow for children with SCZ at municipal level.
21. Acompanhamento das famílias no âmbito do SUAS (Sistema Único da Assistência Social).
22. Widespread inclusion and monitoring of comprehensive health care for mothers or other caregivers.
23. Public financial and service support related to medications and equipment necessary for the monitoring and evolution of children with SCZ.

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24. Refer emergency surgeries for children with SCZ and associated disabilities effectively, with priority given to addressing the problem of shortage of pediatric ICU beds.
25. Avoid the reported closure or reduction of care and services related to children with SCZ resulting from the pandemic.
26. Provide pensions to children with SCZ or other disabilities who are orphaned.

## Researchers

1. Long-term follow-up of children affected by SCZ to understand how children's growth and how COVID has impacted families' lives.
2. Create greater dialogue and transparency with mothers or other caregivers in the production of research data, adding knowledge and views.
3. Greater attention to campaigns to combat arboviruses and provision of information on the sexual transmission of Zika.
4. Interdisciplinary and transdisciplinary dialogues (medicine, social work, education, physiotherapy, etc.) on research results and applications to reduce the fragmentation of research-related actions.
5. Pay attention to new births suspected of being related to congenital Zika syndrome instead of neglecting the importance of this information.
6. Greater support and funding for the continuity of research related to the Syndrome and its impacts on the lives of the people involved.
7. Integrate research with social movements/associations to increase relevance for populations, communities and families.
8. Resume practices for sharing research results that have been postponed and canceled due to the advent of COVID-19.
9. Strengthening social income programs, recognizing their effectiveness in contributing to reducing the impact of diseases.
10. Carry out research and attention to care on the effect of the death of family members during the pandemic on the care of children with SCZ.
11. Study the long-term effects of COVID-19 sequelae on children and families.
12. Greater attention to the sexual and reproductive health of mothers or other caregivers and couples.

**Participants:**

- Mothers: Suzana Lima; Inabela Souza; Marcione Rocha; Andréa Avelino.
- Associations: Pollyana Dias – AMAR; Germana Soares – UMA.
- Service providers: Regina Coeli Ramos; Laura Patriota; Graça Lobo; Michelle Rodrigues; Rose Magna.
- Researchers: Tereza Maciel Lyra; Bernadete Peres Coelho; Sandra Valongueiro.
- Group Reporters: Ana Katarina de Brito; Carolina Albuquerque; Raquel Lustosa Alves; Luciana Campelo de Lira; Silvana Sobreira de Matos; Fernanda Meira de Souza; Diego Rodrigues; Thaiza Raiane Vasconcelos Canuto; Parry Scott,, Marion Quadros.

Debated and approved in a Forum with a total of 50 people on September 22, 2021, and approved as a motion in the plenary of the IV Health Anthropology Meeting, September 24, 2021.

## Resumo

### *Fim de emergências de saúde inacabadas e as redes de cuidados com a síndrome congênita do Zika vírus*

Entendendo que problemas de saúde sempre são inacabadas, este trabalho examina consequências da declaração do fim de uma emergência de saúde sobre práticas de diferentes redes de cuidado interconectadas. Parte da pesquisa Etnografando Cuidados: estudo de caso qualitativo de três documentos produzidos depois do anúncio do fim da epidemia da síndrome congênita de Zika vírus. Mostra contextos de produção de narrativas envolvendo redes de pesquisadores, gestores/prestadores de serviço, mães e famílias de acometidos e associações de mães e suas perspectivas diferentes sobre o que é cuidado. Análises de uma apresentação para pesquisadores e de um texto de discussão no IPEA questionam a narrativa técnica da celebração do fim da emergência com base em conhecimento e atendimento, sem tomar em conta a importância dos cuidados relacionais e afetivos e políticos (das redes de mães/familiares e de associações), deixando-os invisibilizados. Descreve o processo da elaboração da moção para o Fórum Zika na Pandemia, elencando e sistematizando propostas de ações através de um diálogo explícito entre integrante das diferentes redes para abordar questões inacabadas pós-emergenciais. Sugere que práticas semelhantes de diálogo entre redes possam promover maior inclusão e sensibilidade a cuidados que contribuem para diminuir sofrimento e defender direitos de pessoas que continuam a conviver cotidianamente com uma síndrome ou doença cujas consequências persistem.

► **Palavras-chave:** Síndrome congênita do Zika vírus. Fim de emergências de saúde. Narrativas de sucesso e sofrimento. Redes de cuidados.

