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JEAN SEGATA

Chikungunya in Brazil, an Endless Epidemic

▼ **SPOTLIGHT ARTICLE** in *How Epidemics End*, ed. by Erica Charters

▼ **ABSTRACT** This article examines how chikungunya virus disease is epidemiologically and politically invisible in Brazil, unlike other diseases related to the *Aedes Aegypti* mosquito, such as Zika, dengue, and yellow fever. It demonstrates the intricacy of identifying the presence of chikungunya, as its effects are generally materialised in pain, which is difficult to measure and quantify, and thus is invisible to medical and state bureaucracy. As with other chronic diseases, chikungunya transforms identities and social relations among those affected. By analysing the situation in Natal, in Northeast Brazil, and considering epidemics as social, economic, and political narratives as well as biomedical phenomena, the article asks how chikungunya might end when it has not even officially started.

▼ **KEYWORDS** Chikungunya, Epidemics, Invisibility, Anthropology, Northeast Brazil

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"The pain remains; it does not let me forget. I cannot even open a bottle of water. It hurts too much," said Dona Linda. It was March 2021, and we started our conversation by talking about COVID-19. I wanted to know how she, her friends, and relatives were going through such a hard time. She told me about the fear of getting sick and the sadness for her friends who had died, as well as her expectations for the vaccine and hopes for better days. Her complaint of pain was not the result of the current pandemic. It was chikungunya. Dona Linda fell ill 6 years ago after she became infected in 2015. Since then, she lives with the sequelae of the disease, especially a pain in her joints that does not go away. Using the methodology of anthropology and ethnography, I have collected stories like hers by chatting on WhatsApp groups,

Jean Segata • Federal University of Rio Grande do Sul, Brazil, correspondence: Department of Anthropology, Federal University of Rio Grande do Sul, 9500, Bento Gonçalves Ave., Building 43322 (IFCH), Room 226A, 915009-900, Porto Alegre, Brazil. jeansegata@ufrgs.br

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contrasting the lived experience of the disease with bureaucratic and public health policy approaches to chikungunya in Northeast Brazil.

Chikungunya disease is a viral infection transmitted by the *Aedes Aegypti* mosquito. It causes fever and severe joint pain. In Brazil, the first cases were confirmed in August 2014 and increased the following year, at the same time that the Zika virus started to attract international attention. From that time until March 2021, when Dona Linda and I talked, Brazil had already identified more than 970,000 cases, 627,390 of which were confirmed—a monthly average of 9,226 confirmations of the disease—mainly in the Northeast region of the country.[1] Even though outbreaks have spread to all regions of the country, Chikungunya fever is still obscure compared with the other arboviruses that afflict Brazil, lacking public health policies dedicated to the disease and its long-lasting effects.

Recently, Charters and Heitman have established a multidisciplinary agenda to examine how epidemics end. Their analysis shows that "few epidemic diseases are eradicated. Far more often, an epidemic is declared to have ended once the disease falls to endemic levels, when it becomes an accepted, manageable part of normal life in a given society."[2] Also, there is no single end: complex and diverse actions such as vaccination, or medical, social, or environmental interventions suggest a diversity of ends and challenge linear epidemiological narratives, which usually establish a beginning, a peak, and an end for epidemics. The case of chikungunya highlights the diversity and complexity of endings. Yet it also raises the question of what is designated an epidemic, and who writes these political and biomedical narratives. Despite its embodied presence in Dona Linda and thousands of others, the chikungunya epidemic has never officially started, and so remains excluded from political and biomedical narratives.

This article examines how chikungunya virus disease is epidemiologically and politically invisible in Brazil, unlike other diseases related to the *Aedes Aegypti* mosquito, such as Zika, dengue, and yellow fever. Chikungunya has remained invisible to non-sufferers for two reasons. First, Global Health's policy focus on mosquitoes—what has been called mosquito-centrism—results in chikungunya being described and categorized as one more arbovirus transmitted by the dengue mosquito, highlighting universal indicators (such as mosquitoes) rather than local contexts. Chikungunya is therefore not understood as an epidemic in Brazil through its own intrinsic qualities. Second, the nature of chikungunya renders its presence difficult to identify. As its effects are generally materialised in pain, which is difficult to measure and quantify, the disease is often invisible to medical and state bureaucracy. Public health policies for arboviruses tend to respond to critical events, such as outbreaks, but not to prolonged ones, such as the lasting and chronic effects of an infection. As long as the epidemic remains invisible, it will remain endless.

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1 Official numbers from Chikungunya in Brazil obtained from the Notifiable Diseases Information System (SINAN—Sistema de Informação de Agravos de Notificação), Ministry of Health, Brazil (2021a). According to the Brazilian Ministry of Health, in 2020 and 2021, cases are underreported due to the concentration of efforts around the COVID-19 pandemic.

2 Charters & Heitman (2021, p. 211).

Furthermore, as with other chronic diseases, chikungunya transforms identities and social relations among those affected. Pain, even though it is embodied as part of a sufferer's identity and history, can too easily disappear when defined by public policy, biological health, or even administrative bureaucracy. While the chronic pain that chikungunya causes can fit in the nebulous zone described as a manageable part of a normal life at the end stages of an epidemic, then pain as an experience exceeds these parameters. Pain as a lived experience is more complex than the chronic pain that biology recognises as sequelae of infection. It involves memories; it inscribes biographies and transforms histories. As an embodied experience, the epidemic has no end.[3]

Just a "*Puxadinho*"

For 6 years, I conducted ethnographic research examining public health policy for dengue in Brazil and Argentina.[4] The research consisted of observing public policy managers and digital technology experts, and participating in health workers' visits that to areas that the surveillance system put under risk alert. I did what is called mosquito hunting, identifying breeding spots and trying to eliminate eggs and larvae using poison, especially in water reservoirs. Emerging biosecurity interventions shaped dengue policies by focusing on surveillance and mosquito control through modelling and geolocation software, data-mining systems, and DNA technologies for viral mapping. My point was to analyse how these technologies, acting as global frames of preparedness, changed local sensibilities regarding vectors and pathogens, as well as how such technologies replaced an analysis of—and even concealed—deep structures of inequality, environmental racism, and social injustice.[5]

As soon as I started fieldwork in Natal, capital city of the Rio Grande do Norte, in 2015, rumours about a new type of disease gained momentum. Many said it was a different kind of dengue—in some cases milder, in others quite painful. Before long, we learned that Zika had broken out in Northeast Brazil, followed by chikungunya. Health workers I had met were almost all men and had already gotten dengue, chikungunya, and Zika. However, they usually complained most about chikungunya. "It hurts too much; it knocks us down. It is the worst," they said. This gender

3 As Vargha (2016) has noted, "diseases are often imprinted on the bodies of survivors, societies and cultures. Epidemics may change economic structures, social interaction, shape practices of international intervention and attitudes towards healthcare. In some cases, the proclaimed end of a disease leaves individuals or whole societies and states without resources previously guaranteed by the perceived epidemic threat. In others, the action of looking back after the end creates space for making moral judgements on individuals, societies, governments and international organizations."

4 I did fieldwork in Natal, Northeastern Brazil (2015–2016), Porto Alegre, Southern Brazil (2017–2018), and Buenos Aires (2017–2019). The research was supported with grants from the Brazilian National Council for Scientific and Technological Development (CNPq—n. 404715/2018–2014 and n. 308278/2018–2016) and from National Scientific and Technical Research Council of Argentina (CONICET—*Programa salud, ambiente y trabajo PDTS16*).

5 Farmer (2003); Biehl & Petryna (2014); Segata (2017; 2019).

component was significant. They always said they were not afraid of the mosquito because they were strong and "prepared for fighting." They embodied the military imaginary that has shaped public health since the Rockefeller Foundation's time in Latin America. In this approach, outbreaks, epidemics, and pandemics are a matter of war—a kind of military campaign—rather than an issue of health and care.[6] However, in their words, chikungunya was "dangerous" because it attacked their joints and took away their ability to fight.

In contrast, Zika did not worry the men so much, as the pain was much lighter. Compared with other infections, "Zika was a joke." This thinking only began to change the following year, when numerous Congenital Zika Syndrome (CZS) cases, whose most prominent symptom is microcephaly, began to appear. This was also one of the main reasons that led the World Health Organization (WHO) to declare Zika a Public Health Emergency of International Concern (PHEIC) on February 1, 2016 through to November of that same year[7]. Despite the relatively mild symptoms, the severity of the infection has become an issue, especially for pregnant women. Although in less representative numbers than dengue and chikungunya, Zika dominated the epidemiological discussion.[8] Consequently, it mobilised different agendas such as those on human rights, care, and disability, and the feminist agenda for the decriminalization of abortion.[9]

Asking health workers about the lack of specific policies for chikungunya in Rio Grande do Norte, I heard from them that it was just a "*puxadinho*." *Puxadinho* is a typical Brazilian expression for a little makeshift outbuilding to the main house, built to accommodate family growth. Their answers clarified to me that they wanted to talk about Zika since it had become a "superstar" disease by being declared an international threat. Before this, the focus had been on dengue, but it had little "glamour" because people were already too used to it, they told me. "It is like a cold. It will be hard to find someone around here who has never had it," said Carlos, one of the most experienced health workers, acting as Natal's policy managers. Nevertheless, for him, dengue was still the chief problem.

After 30 years, awareness campaigns against dengue no longer worked in Natal. Usually, these campaigns warn against water accumulation, and so to be careful with garbage, discarded tires, or flowerpots, as the mosquito usually lays eggs in water that collects in these places. However, Carlos explained that people no longer cared about the mosquito because "everyone had already fallen ill," so they felt naturally immunised. Yet this was not true, as four different serotypes of the disease still circulated in Natal. Consequently, chikungunya and Zika were important to Carlos because they helped in the actions against dengue: "they brought visibility again

6 Espinosa (2009); Palmer (2010); Löwy (2017).

7 World Health Organization (2016).

8 In official numbers, between 2016 and 2021, Brazil identified 970,000 cases of Chikungunya, 383,499 cases of Zika and 6,840,667 cases of dengue: Ministry of Health, Brazil (2021b; 2021c). In comparison, Zika's cases represented approximately 30% of chikungunya fever cases and 5.5% of dengue fever cases.

9 Diniz (2017); Greenberg (2018); Johnson (2017); Rasanathan, MacCarthy, Diniz, Torreele, & Gruskin (2017); Valente (2017); Williamson (2018).

to the mosquito," he said. To attract attention, the new advertising policy declared that "Dengue mosquitoes also transmit Chikungunya and Zika." People were taking a little more care of themselves because of the new diseases; this was also useful for dengue rates, "because people were again afraid of the mosquito," explained Carlos. By merging epidemics, the public health workers could move forward with a single, multivalent program. The public policy on dengue that I had examined in Natal expanded its scope to encompass these other two infections. Regardless, the focus remained on mosquito control, despite the numerous differences between those diseases and the different social and legal agendas they provoked. Mosquito-centric approaches and merging arboviruses acts to disguise chikungunya from the public consciousness. Dengue and Zika smothered it, and with no historical force or international attention, chikungunya became epidemiologically and politically invisible.[10] Furthermore, although the Brazilian scientific community develops original research on chikungunya and its effects, the creation of specific public policies demands the political will of a broader complex of agents and interests. It is an aggravated scenario when considering structural violence such as environmental racism, making Northeast Brazil a historically forgotten region.[11]

Believing in Pain

Dona Linda lived in the interior of Rio Grande do Norte. I met her in 2016 through her niece Alice, who like me lived in Natal, the capital city. She also helped create a WhatsApp group, adding friends and relatives who also suffered because of chikungunya. At that time, Dona Linda was already complaining of pain. It had been a year since she had been infected. She was retired and lived in a rural area where she used to take care of her small garden and domestic animals. However, with chikungunya, everything had changed. She could no longer bend down to dig the earth and plant vegetables. She had previously been an active person who liked to dance *forró* with friends and visit her relatives in Natal to enjoy the city's beaches, but the pain made all of this hard.

For the first few months after the illness, she believed that everything would pass. "I had hope, you know. The doctor told me I would get better. But time passed and nothing," she told me. Dona Linda even went to another doctor, who said it was normal because of her age and that perhaps she was prone to osteoarthritis. Chikungunya may have exacerbated this process.

The most common clinical symptoms of chikungunya are headache, muscle pain, joint swelling, and a rash. Typically, they are gone within a week, but in some cases,

10 As Frey & Schädler (2021) note for about energy, although its consumption has increased exponentially since the 19th century, codifications, infrastructures, and representations act directly in the political and social production of the (in)visibility of physical energy and public consciousness of its use.

11 Diniz (2017) demonstrated how the science of the Zika virus produced in Northeast Brazil and the very visibility of the disease had to deal with numerous obstacles to international recognition.

they can last for months and even years.[12] In Brazil, accounts circulated that some doctors did not take long-term sequelae into account and did not medically recognise the pain. Chikungunya pain became a protagonist in labour complaints and legal disputes over individual and collective health and labour rights.

Pedro, a friend of Alice, for example, struggled for nearly 3 years to obtain worker's compensation in court. He had to judicialise his chikungunya pain. In 2015, Pedro lost his job and was accused of lying. After he had chikungunya, he often had pain crises. As he said on WhatsApp, "there were days when it was not even possible to get out of bed, so I missed work. But my boss did not believe in the pain, and started to think I was lazy." Pedro explained that he went to the doctor, but the doctor said he could not offer him a certificate for his employment since he was not sick. Like many other people, Pedro had to prove his pain, and thus prove the long-term medical sequelae of chikungunya.

Anthropologist Roberto Damatta calls the Brazilian way of doing things by circumventing the rules "*jeitinho*"—a way to bend what can often be stringent bureaucratic rules.[13] Such social practices might be why, from the employers' and justice authorities' point of view, it is necessary for workers to demonstrate their case through bureaucratic paperwork and evidence, especially when it comes to taking time off work. Once the paperwork is collected, the lengthy litigation against the state begins as part of the process to guarantee workers' rights, a phenomenon that Biehl and Pertryna describe as the "judicialization of the right to health" in the context of accessing medical treatment in Brazil.[14]

In 2017, labour reform in Brazil made workers' rights more flexible, including the deregulation of paid leave when chronically ill. As a result, since 2017 many employers have been able to deduct days not worked from a worker's salary, mainly for unexcused absences. When illness becomes acute and requires a leave of absence longer than 15 days, it takes more than a doctor's certificate. Instead, what is required is a complete medical report with a set of papers that materialises the disability. To achieve this, the worker must go to the National Social Security Institute (INSS), which can take months due to long queues. Meanwhile, a labourer cannot stop working, even if ill, as they run the risk of losing their job. When a worker receives care, s/he often has difficulty proving that s/he suffers from chikungunya's sequelae because biomedical examination instruments are not well-tuned to capture pain. Bureaucracy thus works to deny the sequelae, making chikungunya invisible.

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12 According to recent reports: "Chikungunya can severely reduce quality of life due to postchikungunya rheumatism that can destroy joints, impair daily life and require treatment with antirheumatic drugs; chikungunya can also worsen pre-existing chronic inflammatory rheumatism. Among confirmed cases of chikungunya in France, 15 months after the acute disease, 57% of the patients were still experiencing rheumatic manifestations. The chronic pain and rheumatism among patients after chikungunya infection might have impact on mental health of patients." Paixão, Teixeira, & Rodrigues (2018, p. 4); Aalst, Nelen, Goorhuis, Stijnis, & Grobusch (2017).

13 DaMatta (1986); Hertzfeld (2021).

14 Biehl & Petryna (2013); Aureliano & Gibbon (2020).

For many sufferers, the pain creates the sensation of an absent body—a body that does not respond, producing a transformation in identity and everyday relations.[15] As Didier Fassin explains in the case of HIV/AIDS, disease can inscribe itself into the social and biological memory of individuals:

> The body is not only the immediate physical presence in the world; it also where the past has made its mark. Or rather the body is a presence unto oneself and unto the world, embedded in a history that is both individual and collective: the trajectory of a life and the experience of a group. The mark of time is engraved so deeply as to be imperceptible: when perceiving ordinary objects and when going about one's daily business, in the wear and tear of the physical organism and the exposure to the risk of illness.[16]

The last time Alice chatted with me, in 2020, she complained how chikungunya had "stolen her quality of life." She complained that she could no longer run or ride a bicycle. She was 24 years old when she was infected with chikungunya in 2016 and lamented having gained a lot of weight since then due to the difficulty in exercising as she usually did before the infection. "It looks like I am fifteen or twenty years older; I have become sedentary. When I try to change my routine, it is worse because the pain comes back," she explained. The pain disrupted her college life. She had difficulty typing on a keyboard because her knuckles hurt the most. As she explained, right after she was infected, her mind wanted her to maintain her active routines, but her body could not do so. Like several people with whom she shared the experience with the infection, Alice had to change her life so that her wishes would correspond to what she called the new and precarious body that chikungunya had bestowed upon her.

Conclusions

The joint chikungunya and Zika outbreak in 2015 in Northeast Brazil, where dengue has been a severe problem since the early 1990s, formed acute-on-chronic events—where those with chronic conditions then experience an additional acute condition or stressor.[17] Such disease events further accentuate conditions of disease vulnerability and structural violence. Amidst this set of combined problems, chikungunya has become an invisible epidemic, with a lack of specific health policies for caring for chronic pain or the disease's sequelae, which are often unmeasured and so not noticed in official medical, legal, or state records. This invisibility adds to the burden of the disease, causing further problems for sufferers trying to access medical, labour, and legal rights.

Mosquito-centric frameworks that merge dengue, Zika, and chikungnya echo the *modus operandi* of 19th-century medicine.[18] The latter half of the 19th century was

15 Kelly & Field (1996).
16 Fassin (2007, p. 175).
17 Farmer (2012).
18 Segata (2021).

characterised by the growth and increased authority of biological thinking about health and disease. Pasteurian microbiology and the European project of modern science joined forces in focusing not on the experience and context of disease, but on what they defined as the agents of disease, valorising universal infrastructures such as viruses, bacteria, protozoa, and vectors. The case of the *Aedes Aegypti* mosquito is emblematic. As the famous "villain" of yellow fever and well-known as the dengue mosquito in Brazil (and also the insect for Zika and chikungunya), it does not only act as a vector of those diseases by transmitting the viruses that cause them. It also "spreads" a particular approach to health, a particular prioritisation of science and technology, corporate interests, and public policies. *Aedes Aegypti* is an infrastructure capable of jumping from one context to another, alongside knowledge, disease models, and medical practices materialising hegemonic fantasies of Global Health, based on "cross-cultural indicators." Yet, focusing on vectors and pathogens obscures the social and embodied experiences of epidemics.[19]

Epidemics cannot be understood solely through biological events alone, whether through infection, contagion, or vectors. They likewise cannot be measured solely by biomedical or bureaucratic parameters. The lived experience of disease, including the chronic and lasting effects of infection and pain, understood within their social and economic contexts, is also required to fully understand their significance.

Charters and Heitman explain that in some cases, the end of an epidemic can be determined by the decline in cases and fatalities, the eradication of vectors, or the non-circulation of pathogens. In other cases, as in continuous or cyclical epidemics such as influenza and HIV/AIDS, the end is unclear. Most of the time, instead of a definite end, the ending of an epidemic is determined by "acceptable levels" of disease:

> The end of disease, may it be a goal, a wish, or a thing of the past, is often perceived in a particular and narrow sense. Endings often imply progress of some kind, while the stories of survivors overwrite the ones of failure, of anonymous loss. But endings are often messier than any international, national or local governing body would care to admit, and most diseases do not map onto neat narratives. Endings hardly mean that the story is finished.[20]

In the case of chikungunya, its social and political nature is shaped by its continuous invisibility. It is an epidemic that cannot end because, according to the prevalent metrics of health agencies, it has never officially begun. In this administrative context —with social and political mechanisms that make the epidemic invisible by normalis-

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19 Responses to COVID-19 are similar. The new coronavirus became the centre of a technocratic and elitist narrative in biomedicine, which shapes the explanation for and responses to the epidemic. The virus is the "transcultural index" of the pandemic; its infrastructure. This pathogen is but one of the protagonists of the present history of the pandemic. Knowing its nature and how it works in our bodies is fundamental, but this approach diverts attention from local factors, shaped by profound inequality and social injustice structures; see Segata (2020); Gamlin, Segata, Gibbon, Ortega, & Berrio (2021).

20 Vargha (2016). See also Charters & Heitman (2021, p. 219): "local communities revive normal patterns of life, dealing not only with the epidemic's repercussions, but also its aftershocks. Thus, the epidemic can be viewed as having ended even as dislocation, cases, and fatalities persist."

ing its problems—patients find it much more difficult to access medical assistance, labour protection, and legal remedies, which makes it more difficult for communities to "revive normal patterns of life."

An endless epidemic. That is how Diniz and Brito summarised the experience of Zika in the lives of Brazilian women.[21] As they explained, this phrase is necessarily contradictory because an epidemic has a beginning, a peak, and an end. However, by examining the experience of illness in their bodies and the fear of Zika during pregnancy, an epidemic becomes a more complex event. In considering the mothers who care for and fight for health rights for children affected by Congenital Zika Syndrome, stigmatised as being "daughters of the mosquito," the epidemic is endless. Chikungunya is likewise endless, with those infected remaining in pain long after the infection is over. It is an embodied epidemic that exceeds its biology.

Chikungunya's persistent pain is not simply one of rheumatic joints; it is a pain that takes shape in absences. Dona Linda's garden can no longer be cared for; her trips to the beach do not happen anymore. It is the *forró* that is not danced. Chikungunya's pain is the job that Pedro lost and the body and quality of life that Alice is left with after her illness. As Moran-Thomas noted in the case of diabetes in Belize, it is the absences—overwhelming but silent—that make the presence of the disease visible:

> I began to glimpse the negative spaces of what was missing: bodies that sometimes slowly stopped healing. Potent medicines and devices that sometimes slowly stopped working. Specters of lifesaving technologies that existed somewhere else in the world. Memories of former vegetable gardens and lost homelands. Loved ones changing in photograph albums. Missing limbs, failing organs. An empty dress left hanging to outline an absence.[22]

More than detecting the end of the circulation of a pathogen or cases of infection and death, epidemics also define individual and collective experiences, and move contingently within a tangle of social, economic, and environmental transformations. If epidemics do not end, what happens to those living in their indefinite and invisible zones of acceptable and manageable levels of disease? How do pain, suffering, and absences end? To end, an epidemic must first exist. For as long as the chikungunya epidemic in Brazil is not recognised, it is impossible to grant sufferers the ability to find its end.

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21 Diniz & Brito (2019).
22 Moran-Thomas (2019, p. 4–5).

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