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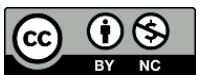

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Summary

The Zika Congenital Syndrome has severe long-term, complex impacts on affected children and their caretakers, demanding state responses even after the withdrawal of the national health emergency status. This paper discusses the narratives and agency roles involved in the policymaking and implementation of a social protection response to the Zika epidemic in Brazil. It analyses the underlying narratives that have framed policy processes related to the Zika Congenital Syndrome both at the national and subnational level in a moment of political and economic crisis, the state of Rio de Janeiro being the case studied.

Keywords: Zika virus, microcephaly, Zika Congenital Syndrome, public policies, policy narratives, epidemic, Brazil, Rio de Janeiro, social protection, health, bureaucracy, gender, disability.

Isabele Villwock Bachtold is a Brazilian anthropologist, IDS alumna and external consultant. She is also a civil servant at the Brazilian Federal Government with more than ten years of experience with social policies implementation and monitoring.

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Acronyms

ANP	Brazilian National Petroleum Agency
BPC	Continuous Welfare Benefit
CRAS	Centro de Referência de Assistência Social (Social Assistance Reference Centres)
CREAS	Centro de Referência Especializado de Assistência Social (Specialized Social Assistance Reference Centre)
COES	Centre of Operations of Health Emergency
EAR	Rapid Strategy of Action
ESPIN	Public Health Emergency of National Concern
FIOCRUZ	Oswaldo Cruz Foundation
GDP	gross domestic product
HDI	Human Development Index
INSS	Instituto Nacional do Seguro Social (Brazilian Institute of Social Security)
MS	Brazilian Ministry of Health
MDS	Ministério do Desenvolvimento Social (Brazilian Ministry of Social Development)
NGO	non-governmental organisations
OHCHR	Office of the United Nations High Commissioner for Human Rights
PBF	Bolsa Família Programme
PHEIC	Public Health Emergency of International Concern
SARS	Severe Acute Respiratory Syndrome
SCZ	Congenital Zika Syndrome
SUAS	Sistema Único de Assistência Social (Unified System of Social Assistance)
SUS	Sistema Único de Saúde (Unified Health System)
WHO	World Health Organization
UFPE	Federal University of Pernambuco
UN	United Nations
UnB	University of Brasília
UNDP	United Nations Development Programme

1 Introduction

In October 2015, the world turned its attention to the Brazilian backlands as microcephaly was increasingly reported in babies born to women infected by the Zika virus during pregnancy. Known since the 1950s, the Zika virus did not raise great concern until 2007, when epidemics reached the Pacific, causing mild symptoms in a small part of the infected population (Avelino-Silva and Kallas 2018). The correlation between the alteration of epidemiological patterns in microcephaly and the Zika virus infection placed the Northeast of Brazil at the centre of global health debates (Diniz 2016). The fact that the neurological alterations were caused by an arbovirus, whose vector – the *aedes* mosquito – was abundant in the country demanded rapid response from scientists, medical professionals, and political authorities. In December 2015, the Brazilian state recognised the cluster of microcephaly cases as dangerous and declared a state of health emergency. Two months later, they were followed by the World Health Organization (WHO).[1]

In recent years, epidemics and so-called 'emerging infectious diseases' have been dominating policy debates, from Ebola to avian influenza to SARS (Leach *et al.* 2007). The study of epidemics is no longer circumscribed to the medical and epidemiological field; there is growing scientific interest in the broader social, ecological, political, economic, and cultural dynamics that shape the emergence of an epidemic and the policy responses to it. Research has consistently shown that epidemics disproportionately affect poor and vulnerable people: while poverty conditions encourage the transmission and persistence of infectious diseases, the outcomes of epidemics contribute to increasing inequalities and vulnerabilities (Farmer 2001; Leach and Dry 2010). Hence, questions around social justice, who is affected and where, and how to address the complex interrelated causes and consequences of epidemics are of great concern to policy discussions.

The Zika Congenital Syndrome[2] (SCZ) represented an unprecedented challenge to public health at the local, national and international levels. The emergence of the epidemic is embedded in a historical system of intersecting inequalities in Brazil, affecting mostly poor and young women (Diniz 2016; Soares 2017; Johnson 2017). While the vertical transmission (from pregnant women to foetus) of the virus raised discussions on reproductive rights, its consequences on child development and increased care demands need to be framed within the wider political economy of unpaid care (Chopra, Kelbert and Iyer 2013; Makina 2009). However, these dynamics have not been at the centre of state efforts in handling the epidemic. State policy responses have been primarily focused on combating the mosquito, setting aside the voices and demands of those affected by the disease (Fleischer 2017; Silva 2017; Diniz 2016).

Despite the reduction in new cases in 2016, which led the Brazilian state and the WHO to lift the status of health emergency, the long-term and severe impacts of SCZ on poor women and children remain. The disease increased social risks and required a state response that went beyond health treatments, epidemiological surveillance, and vector control. This response, for instance, was delineated in a context of economic and political crisis and was shaped by multiple actors, interests, and narratives at the national, state, and municipal level.

This paper provides an exploratory narrative on the process, discourses, and actors involved in developing and implementing social policies targeted at the population affected by the Zika virus. More specifically, it aims to provide a critical answer to the following research question:

1 World Health Organization, WHO Director-General summarises the outcome of the Emergency Committee regarding clusters of microcephaly and Guillain-Barré syndrome (WHO, Geneva, 2016).

2 The neurological complications caused by the Zika virus in foetuses are currently called 'Zika Congenital Syndrome'. This derives from scientific evidence that neurological malformation in children born to women infected by the Zika virus might occur in children with regular head size, not being classified as microcephaly (França *et al*. 2016).

what are the underlying narratives and agency roles in the social protection response to the Zika epidemic by the Brazilian state? Considering that policymaking and implementation are complex and iterative processes (Chopra 2011) that occur at multiple sites and layers, this paper presents the narratives at national and subnational levels that permeated the state response from the epidemic outbreak, in November 2015, until December 2018.

The rest of this paper is structured as follows: after introducing the methodological choices and research processes, I provide the conceptual framework that guided the analysis, followed by the background to both the Zika epidemic outbreak and social policies in Brazil. Next, I examine the dominant policy narratives that shaped the national response in the field of social protection. The context of the state of Rio de Janeiro, the case study of this paper, is presented in the next section, followed by a narrative analysis of sub-national policy responses. Finally, I offer some conclusions and policy recommendations.

1.1 Methods and positionality

The narrative presented in this paper is the result of qualitative research that privileges an interdisciplinary understanding of policy processes. The research was built upon primary and secondary data gathered through document analysis and semi-structured interviews in addition to a review of recent social sciences literature on this topic.[3] Narrative analysis was conducted at the national and subnational levels, with the state of Rio de Janeiro as the case study for this research.

Since institutional and socioeconomic characteristics vary largely among Brazilian states, I focus my research on Rio de Janeiro (henceforth Rio), with some insights from the municipal level. Two reasons have led to this decision. First, this research, although undertaken independently, was conducted as part of a project co-coordinated by IDS/University of Sussex with Brazilian two institutions (the University of Pernambuco and the Oswaldo Cruz Foundation) aimed at investigating the institutional settings, practices, and policies targeting virus-affected populations.[4] Hence, this paper proposes a complementary insight into the fieldwork undertaken by partner institutions. Second, Rio has the third highest number of confirmed cases of microcephaly of Brazilian states[5] and is facing one of the biggest fiscal crises in its history, which has led to considerable increases in levels of violence. Thus, even though Brazil is an upper-middle income country, Rio de Janeiro's specific situation could potentially be relevant to understanding other, less well-resourced countries that have experienced epidemics, such as the Ebola virus in West African countries (Huff and Winnebah 2015; Leach 2015).

Concerning document analysis, I reviewed legislation and official guidelines addressing issues related to the Zika epidemics from the Ministry of Social Development and the Social Assistance and Human Rights Secretariat of the Rio, produced independently or in coordination with other governmental bodies from 2015 to 2018. The review of these documents aimed to achieve three goals: (a) identify the policies, actors, and bureaucratic procedures concerning social policies targeted at populations with SCZ; (b) understand the narratives mobilised in these documents; and (c) analyse which dimensions of the syndrome were included or excluded in these narratives. It was assumed that more than a systematisation of routines and processes, documents are 'social facts', since they are

3 The literature assessed complies ethnographic research, storytelling, papers, and theses in social sciences-related fields and NGOs' reports.

4 The research project, named 'Building Collaboration for 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', receives support from the Newton Fund. It is organised in two axis: (1) care practices and social relations among mothers and caretakers for children with SCZ and (2) public policies and the elaboration paths for intersectoral therapeutic care for the population. This paper is mostly concerned with the second axis.

5 In absolute terms, Rio de Janeiro had 291 confirmed cases. When considering notifications, Rio ranks the fifth place: 1,137 cases (Ministério da Saúde 2018).

formulated, shared, and used in socially organised ways (Atkinson and Coffey 1997), which produce effects in reality (Lowenkron and Ferreira 2014) and re-construct categories of an individual or groups in the face of the state (Peirano 2002).

Eight face-to-face semi-structured interviews were conducted in Rio[6] with social workers and bureaucrats from the state and municipal level. Two other interviews were held through Skype with officials from the Federal Government. While the heterogeneity of the respondents does not allow for generalisations about a specific work category, it provides a broad view of the various layers of policymaking and implementation. As a common feature, all interviewees worked directly or indirectly with social policies targeted at the population with SCZ.

The interviews followed an initial script but were adapted according to the respondents' occupation. They were conducted for two main purposes: (a) to understand the implementation of existing policies and programmes, and (b) to assess the interviewees' experiences and perceptions about the state responses to the epidemic and their agency in these processes.

In this regard, I share the assumption that interviews are not an impartial tool to collect data. Rather, they are 'negotiated texts' between the researcher and the respondents that are shaped by the context in which they occur (Fontana and Frey 2000); interviews are the outcome of a social encounter where the answers depend on the interactions and impressions of both the interviewer and the interviewee (Dingwall 1997). Hence, while I opted for relatively vague questions which allowed the respondents to bring into discussion the issues they want to disclose. I also did not refrain from sharing feelings and thoughts born from my own experiences. This was a conscious decision to create a level of mutual confidence, as well as to give room for more sensitive issues and subjective opinions.

A narrative approach was applied both as a method to analyse the findings and as a conceptual framework.[7] Instead of treating interviewees' answers as 'true pictures of reality', a narrative analysis opens up for understanding how respondents and researchers, in concert, generate plausible accounts of the world (Silverman 2000: 823). It assumes that narratives and storytelling are methods of sharing information influenced by context, practices, and circumstances (Marvasti 2004). In this regard, a narrative analysis was constructed through a process of 'bricolage'[8] (Levi-Strauss 1966; Dezin and Lincoln 1999; Rogers 2012), by assembling elements of different narratives into a new one. Hence, this paper builds upon the assumption that the product of a research effort – a written text – is a 'story in its own right' (Marvasti 2004: 18).

As a narrative in its own right, I must acknowledge that this text presents one way, among many possibilities, of telling the story of the Zika epidemic in Brazil and its social, political, and institutional consequences. It is a personal endeavour to critically engage with the intersections of actors and discourses involved in the policy process targeted at the virus-affected population. Thus, the emphasis of this paper is on the Brazilian state and its bureaucrats' narratives. Although it could be argued that this paper reflects only one side of the story, I decided not to engage with civil society and the affected population due to time

6 One interview involved three people at the same time (a medical doctor and two social workers). In total, 11 people were interviewed.

7 See Section 2 about policy narratives (Leach and Dry 2010; Scoones *et al*. 2006).

8 In his book The Savage Mind (1966), Lévi-Strauss used the notion of bricolage to describe the process of meaning-making in mythological thought. The French expression denotes the practice of using whatever is at hand and reassembling them to create something new. This concept has been used in qualitative research to embrace a multiplicity of political, epistemological and methodological approaches to inquiry (Roger 2012). According to Denzin and Lincoln (1999) this approach enables researchers to respect the complexity of the meaning-making and research process.

and ethical constraints.[9] The alternative narratives are, then, secondary to this research and were convened through a literature review.

I also recognise that my positionality as both an anthropologist and a civil servant from the Brazilian Federal Government has influenced the interviewees' own narratives, and has also permeated the whole processes of researching and writing of this paper. In addition, it is worth noting that the interviewees were those who were willing to speak and, thus, tended to be more active or sensitive to the topic, while holding more critical perspectives on the state responses.

2 Conceptual framework

This paper draws on a conceptual framework that casts aside the static, linear, and rational perspective of policy processes in favour of an approach that embraces the messiness, complexity and fluidity through which policy is experienced, formulated, and implemented by a wide range of actors (Scoones *et al.* 2006). It is, thus, influenced by the field of Anthropology of Policy (Shore and Wright 1997; Wedel *et al.* 2005; Shore 2013), the concepts of policy process, narrative, and framings (Scoones *et al.* 2006; Leach 2010) and literature on local-level actors and bureaucrats' agency (Lipsky 1980; Goetz 1997).

2.1 Anthropology of policy

Policies are increasingly becoming the subject of anthropological enquiry (Shore 2013). An anthropological approach privileges an understanding of policies as both performative and productive, constituted by and constitutive of the actors, institutions, and instruments that mediate policy processes (Wedel *et al.* 2005). Anthropologists are concerned with the complex ways in which concepts, organisations, and actors interact to consolidate regimes of power and knowledge or to create new modes of governance (Shore 2013). Hence, issues of how language and discourses are used to label groups, frame problems, and depoliticise policy decisions are at the core of anthropological debates (Sutton 1999). There are no clear-cut boundaries between political and technical decisions; rather, technical language is used to portray policy as a neutral, value-free realm (Shore and Wright 1997).

The definition of policy, then, depends on the context in which it is embedded, and the actors involved; policy is a 'social and cultural construct' that needs to be unpacked to be understood (Shore 2013: 90). Consequently, examining the assumptions and framings of a policy debate should be the starting point of anthropological research (Wedel *et al.* 2005). It requires what Reinhold calls 'study through': 'tracing the ways in which power creates webs and relations between actors, institutions and discourses across time and space' (as quoted in Shore and Wright 1997: 14).

2.2 Policy processes, narratives and framings

A more instrumental approach that resembles most of the anthropological assumptions is the notion of 'policy process' presented by Scoones *et al.* (2006). The authors propose a framework to understand the complexities of policy dynamics that link three interconnected themes:

9 The interviews were conducted during three-weeks of fieldwork in Rio de Janeiro. I considered this time not enough to create confidence and emotional linkages with the mothers and caretakers of children with SCZ in order to allow a sensitive engagement. Besides, these women are already overwhelmed by the social burden imposed on them, since they are responsible for care practices and therapeutic treatments (Lira *et al.* 2017; Fleischer 2017). Despite consuming their time, a careless, impersonal research approach could reinforce their position as 'the researched object', and is against my ethical and personal commitments.

1 Policy Narratives – related to discourses and knowledge practices; the 'stories' that describe policy problems and provide explanations about their origins and suitable interventions. It defines 'what is wrong and how it must be put right' (2006: 10).
2 Actors and networks – those involved in policy processes and the connections and alliances between them (coalitions, institutions, individuals). They are relevant for spreading and maintaining narratives, setting agendas and influencing decisions.
3 Politics and interests – policy processes are value-laden, shaped by politics. They are influenced by interest groups that exert power and authority at each stage of the process.

The interlinkages of these three themes limit the 'policy space' for changing and influencing policy processes. According to the authors, policy space is the extent to which a policy maker's actions are limited by dominant narratives, interests and actors (2006: 14). It is an actor's room for manoeuvre that can change the course of the action, allowing space to consider alternatives or a wider set of options (Sutton 1999).

In this regard, policy processes addressing diseases and epidemics are delineated by narratives that legitimise and construct different pathways of responses – what Leach and Dry (2010) name as 'epidemic narratives'. The authors argue narratives are more than storylines, they are 'stories with purposes and consequences', with practical and material impacts for those affected (Leach and Dry 2010: 6). How an epidemic is defined in space and time, which of its implications are addressed, and who gains or loses, depends on who gets to do the framing (Leach and Dry 2010: 5). Here, the notion of 'framing' is crucial to understanding the policy process. It assumes that the boundaries of a complex system[10] are open to multiple forms of interpretation; what is considered as relevant for a policy process (knowledge, evidence, problems, entities) is defined by who sets the framing. On this point, Leach and Dry (2010: 9) recognise that there are multiple epidemic narratives, shaped by social, institutional, political contexts, and power relations; while some are translated into pathways and responses, others remain silenced and marginalised.

2.3 Bureaucrats and agency

Along these lines, the emphasis is given to the agency of individuals in policy implementation, a process that is seen as a mere administrative task in the mainstream literature (Sutton 1999). In contrast, Lipsky (1980) argues that street-level bureaucrats play an active role in shaping and adapting public policies through their routine practices. They exercise wide discretion in decisions during their daily encounters with citizens, based on their own worldview and moral values and constrained by adverse work conditions and real-life demands. In this regard, fieldworkers are de-facto policymakers, affecting the programme outcomes and the knowledge that informs policy process (Goetz 1997).

Increasingly, recent literature on policy studies is drawing on the role of mid-level bureaucrats, a category that lies between high-level politicians and local implementers (Pires 2012, 2018; Cavalcante and Lotta 2015). They translate decisions into actions, a necessary step in the execution of policies, but their level of agency or influence depends highly on institutional contexts (Pires 2018). In some cases, those bureaucrats might transform institutions from within, or promote change through small wins (Eyben 2013).

In accordance with the policy process approach, this literature questions the dichotomy between policymaking and implementation. A policy process is a 'diverse, diffuse, complicated activity', where actors' positions and agency might compete or overlap (Keeley and Scoones 2000: 90). In this sense, despite not neglecting the importance of interests and politics, this paper focuses on the actors, networks, and policy narrative aspects involved in

10 According to Leach *et al*., a system is constituted of 'social, institutional, ecological and technological elements interacting in dynamic ways' (2010: 43).

social protection policy responses to the Zika epidemic. After a preliminary data analysis, I conclude that a classical political economy analysis based on interests does not have enough explanatory power in the specific context I am examining.

2.4 Social protection policies

Finally, a brief clarification on what is considered as *social protection policy* is needed. This notion is debated by a broad set of literature and from diverse frameworks and, despite the consensus about the importance of social protection, its conceptual definition remains open to interpretation (Devereux and Sabates-Wheeler 2007; Gentili and Omano 2011). A wider definition might include social assistance, cash transfer programmes, services (education, health, nutrition), labour policy and insurance. (Gentili and Omano 2011). In the Brazilian case, this definition would be closer to the constitutional concept of *seguridade social*, or social security, that involves social assistance (non-contributory), labour insurance, and health policies.

In this paper, I adopt a narrow and more instrumental view of social protection, mainly addressing governmental cash transfers and social assistance sectors, while setting aside health policies – although these areas may overlap in practice. I've made this choice for three reasons: (1) to limit the scope of this paper; (2) to provide a complimentary discussion to the existing literature on policy responses to the Zika epidemic, that mostly address the health sector; and (3) to approximate the term to its frequent use by Brazilian administration.[11]

3 National context: epidemic outbreak in a moment of political crisis

Before continuing, it is necessary to provide some context. Since this paper addresses the social policies targeted at the population infected by the virus, a contextualization on the outbreak of the syndrome is provided in the first part of this section. The second part provides a brief historical narrative on social policies in Brazil and the current context of economic and political crisis.

3.1 Zika virus epidemic in Brazil

In the second half of 2015, neuropediatricians from the Northeast of Brazil noted an unusual increase in the number of children born with microcephaly. The alteration in epidemiological patterns of microcephaly and the cluster of cases led the government to launch a national surveillance system in December 2015 (Ministério da Saúde, 2015b) and declared it as an Event in Public Health of National Concern (ESPIN) shortly before the correlation between the Zika virus and foetal neurological disorders was confirmed (Brasil *et al.* 2016; Oliveira *et al.* 2017). In February 2016, the WHO declared a Public Health Emergency of International Concern and accepted the indicators of causal association between the Zika virus and microcephaly one month later (França *et al.* 2016).

By December 2018, there were 3,279 confirmed cases (out of 16,900 notifications) of children affected by SCZ in Brazil, most of them located in poor and vulnerable areas (Ministério da Saúde 2018). The epidemic highlighted the difficult living conditions of many marginalised families and emphasised the complex and longstanding challenges in public

11 This assumption is based on my own experience as a civil servant from the Ministry of Social Development and from the interviews conducted for this paper.

health, social development, infrastructure, access to water and sanitation, gender relations, and reproductive rights in the country (Human Rights Watch 2017).

The emergence and consequences of SCZ need to be situated within the wider system of gender, race, class, and regional inequalities that allowed the epidemic and its pernicious effects to occur (Soares 2017; Silva *et al.* 2017). The epidemic has disproportionately impacted poor women and girls in northeast Brazil. In the first months of the epidemic, 97 per cent of the cases were concentrated in this region (França *et al.* 2016). Affected families typically lived in vulnerable areas without water treatment and sanitation, which favoured the proliferation of the vectors (Human Rights Watch 2017). Furthermore, limited access to contraception methods and restrictions on sexual and reproductive rights in Brazil means that poor, non-white women are less able to plan their pregnancies or access proper healthcare (Diniz 2016). Traditional gender roles in the country also intensify the social and economic burden of the disease on women (mothers and grandmothers) since they are more often responsible for the care and treatment of children affected by SCZ (Fleischer 2017; Scott 2017b, forthcoming).

Although the Zika virus only reached Brazil in 2014, its vector, the mosquito *aedes*, had been identified in the country long before. Other epidemic arboviral diseases, spread by the same mosquito, such as dengue and yellow fever, were common in Brazil and mostly affected impoverished areas characterised by inadequate access to water, sanitation, and safe garbage disposal. Regardless of pre-existing high infection rates, structural problems have not been at the centre of governmental efforts to combat these diseases. State responses have focused on curbing mosquito populations through insecticides and biochemical productions and the ‘education' of people about vector reproduction, thus implying that the responsibility for these epidemics lay with those most affected by them (Diniz 2016; Silva *et al.* 2017).

Confirmation that microcephaly cases in the northeast of the country were caused by a virus transmitted through the *aedes* attracted worldwide attention and required rapid responses, financial investments, scientific research, and the reorganisation of public services. These joint efforts led to the reduction of notified cases at the end of 2016, saving Brazil's reputation about its capacity to deal with the epidemic (Scott 2017b, forthcoming). However, the long-term effects of the epidemic on health are yet unknown, and many uncertainties remain about the consequences of the virus for children’s development. In this regard, important dimensions of the epidemic received less attention and public investment, such as sexual and reproductive health, infrastructure, and social protection policies, despite constant demands from the population affected, civil society, and activist movements (Scott 2017a).

3.2 Social policies in Brazil and the crisis context

In the last two decades, Brazil has made remarkable progress in reducing poverty and fighting hunger in its territory; yet, the country is among the most unequal in the world (Morgan 2017; OXFAM 2017). Between 2004 and 2014, more than 28.6 million people were lifted out of poverty[12] as a result of the economic growth and the implementation of a robust social protection system, which involved both contributory and non-contributory benefits and public investments in health and education (Robles and Mirosevic 2015). However, since 2015, the pace of poverty reduction has reverted (Skoufias and Gukovas 2017), and the sustainability of the achievements in this field are under serious threat from the current economic recession, political crisis, and austerity measures.

The foundation of the social protection system in Brazil derives from the 1988 Constitution, which recognises the state’s responsibilities in promoting social security, health, education,

12 www.worldbank.org/en/country/brazil/overview

and labour to all citizens. Enacted during the democratisation period, the 1988 Constitution has re-organised the countries' social protection scheme, assuring decentralisation and social participation in the implementation and management of policies, while establishing centralised taxation and inter-redistribution of revenues (Franzese and Abrucio 2009; Arretche 2016). Legislation approved in the following decades tied the spending of subnational governments to health, education, and social protection, limiting the discretion of local governments (Arretche 2016).

Among other important innovations in public policies, the 1988 Constitution created the Unified Health System (Sistema Único de Saúde – SUS). The SUS ensures universal, free, public-funded, and rights-based healthcare through institutional mechanisms that define federal, state, and municipal responsibilities. It integrates all three levels of complexity – basic, intermediate, and high (Coelho and Shankland 2011).[13] However, despite substantial progress in national health indicators, the system still faces challenges in the quality of service provision, especially for the poorest populations.

The 1988 Constitution also laid the groundwork for a series of policies that later became the Unified System of Social Assistance (Sistema Único de Assistência Social – SUAS), launched in 2005. According to its regulation, the SUAS is responsible for ensuring the following securities: autonomy, coexistence, income, and survival of circumstantial risks (Jaccoud *et al.* 2010). The system's institutional organisation was based on the SUS, involving social participation and the decentralisation of services, but with less autonomy at the state and municipal levels. Services are provided by local facilities, namely the Social Assistance Reference Centres (Centro de Referência de Assistência Social – CRAS) and Specialised Social Assistance Reference Centres (Centro de Referência Especializado de Assistência Social – CREAS) at the territory level.

In addition, non-contributory cash transfers have played a critical role in reducing poverty rates in the country (Skoufias and Guovas 2017). Among those, two programmes are especially notable: the Bolsa Família Programme (PBF) and the Continuous Welfare Benefit (Benefício de Prestação Continuada – BPC). The first is widely recognised for its success in aligning cash transfers with education and health conditionalities for more than 13 million beneficiary families.[14] The second represents a significant achievement for the rights of elderly and people with disabilities, although it is less known internationally. Also established by the 1988 Constitution, the BPC provides unconditional, guaranteed monthly income equivalent with the minimum wage, to persons with disabilities or people above the age of 65 who can prove they have no means of supporting themselves. Despite the smaller number of beneficiaries (4.5 million in 2017), the BPC is the biggest cash transfer programme in Brazil terms of budget allocation (MDS 2018a).

The widening of social policy coverage, scope, and expenses are considered by many as the legacy of the Workers Party and its leader, the former president Luiz Inácio Lula da Silva who served from January 2003 to December 2010. In the last years, Brazil's social assistance and safety net played a critical role in safeguarding social gains and preventing more Brazilians from falling into poverty (Skoufias and Guovas 2017). However, while the current fiscal and economic crisis[15] has led to increasing unemployment rates, social policy

13 According to Shankland and Coelho (2011), during the 1990s, the National Ministry of Health, states, and municipalities signed several agreements which defined a clear division of labour, responsibilities, and financing within the SUS. The current institutional arrangements work as described: 'The MS establishes national guidelines for healthcare at all three levels of complexity (basic, intermediate and high) and provides financial support to states and municipalities. States coordinate services provided within their territory, linking basic, intermediate, and highly complex services. Municipalities are responsible for provision of basic care and referral of patients to more complex services' (2011: 50).

14 www.mds.gov.br

15 Brazil is currently undergoing a deep recession. GDP contracted 3.8 per cent in 2015 and 3.5 per cent in 2016 and the unemployment rate is at 12.4 per cent. The economic crisis resulted from a combination of factors, including the fall in commodity prices, the inability to make fiscal adjustments, and domestic political instability. www.ibge.gov.br

coverage has been decreasing since 2015 (David *et al.* 2018) due to several fiscal adjustments and reforms imposed by former president Michel Temer after the impeachment of his predecessor Dilma Rousseff in 2016. Social policies were severely affected, caused by budget cuts, the review of rules and eligibility criteria, and stricter control measurements. A greater impact is expected to be felt in the near future as a result of the Constitutional Amendment n°95/2016 that imposes a cap to government expenditures for the next twenty years. Some estimate that this spending cap will raise poverty rates and vulnerabilities (Paiva *et al.* 2016), increase child mortality (Rasella *et al.* 2018), and breach human rights (David *et al.* 2018; OHCHR 2017), causing a huge recession in social protection policies throughout the country.

The next section presents the national policy narratives embedded in these broader contexts that affect the social policy responses to the Zika epidemic in Brazil.

4 National policy narratives

The formulation of a national response to the cluster of microcephaly cases started in November 2015, with the creation of the Centre of Operations of Health Emergency (COES)[16] coordinated by the Ministry of Health. The actions were consolidated in a strategy, the National Plan for the Combat of Microcephaly (Ministério da Saúde, 2015b) which was launched by the Federal Government in December. The plan was composed of three axes:

- mobilisation and control of the mosquito;
- provision of treatment and public services to the affected population; and
- research, education and technological development.

The Ministry of Social Development was later involved in the official talks, driven by two main demands: combat *aedes* through the SUAS network (CRAS and CREAS, due to their capillarity in the territory) and develop or adapt its services to better assist the virus-affected population.

In recognising that the increasing number of confirmed cases demanded integrated actions from both sectors, the ministries launched a joint strategy of SUS and SUAS. The Rapid Action Strategy (Estratégia de Ação Rápida – EAR) organised health and social assistance facilities to locate children with confirmed or suspected cases, refer them to adequate health treatments and fast-track their families' access to social programmes and benefits (Ministério da Saúde and Ministério do Desenvolvimento Social 2016b). The integration of operational procedures and routines were detailed in two joint guidelines for states and municipalities. The documents prescribed information flows and actions both to combat the vector and to assist children and pregnant women (Ministério da Saúde and Ministério do Desenvolvimento Social 2016a; 2016c). Special attention was given to the BPC: some procedures were adapted to support the families with the administrative requirements (e.g. scheduling of appointments and the provision of medical report at the diagnosis center instead of at the National Insitute of Social Security – Instituto Nacional do Seguro Social – INSS) and priority access to the benefit was given to children with microcephaly (Governo do Brasil 2016). However, no changes were made in the income eligibility criteria.

Despite being described as technical and administrative procedures, the social protection response to the Zika epidemic clearly involved political choices and decisions which shaped the pathways of state action. In this regard, analysing which narratives have framed the

16 The Centre gathered different sectors of the Ministry of Health in weekly meetings to monitor epidemiologic reports, discuss investigations on the cause of the epidemic, and propose procedures to be followed by states and municipalities (Soares 2017).

official response is critical to understanding which pathways became justified and dominant, which had 'profound practical and material implications for how successful responses [were], gauged in which terms, and for whom' (Leach and Dry 2010: 6). In the following lines, I present four of the dominant narratives that shaped the national social protection response to the Zika virus epidemic in Brazil.

4.1 Austerity narrative

As mentioned above, Brazil has been in an economic recession since 2014. The recessive macroeconomic policy adopted during Dilma Rousseff's second term deepened the effects of the crisis and was instrumental Rousseff's impeachment (Carvalho 2018). After Temer took power, an austerity agenda was imposed and justified as the only way to boost economic growth. The crisis was framed around the claim that the fiscal adjustments made so far were insufficient, as the public budget was no longer enough to cover the social rights conquered by the Brazilian population since the democratisation period. The fiscal deficit was consequently blamed on the expansion of the social security network, and social investments were identified as the main cause of recession. The government's responses involved the above-mentioned cap to governmental expenditures, labour law reforms, and budget cuts in social policies. These were top-down measurements, implemented without wider public debate (David *et al.* 2018).

The austerity narrative, aligned with a moral discourse to combat corruption, was also manifested in the 'targeting' controls imposed on social programmes, implemented since 2016. Right after Rousseff's impeachment, the Minister of Social Development declared the need to 'clean' social programmes and 'find the deceivers'.[17] The Federal Government established several task forces to promote database cross-checks and identify those who were 'lying' to fit in the eligibility criteria, imposing additional controls and changing rules to make access to the benefits more difficult.

In the context of the Zika epidemic, the austerity narrative not only hampered access to social programmes for affected families but also limited the budget available for social protection and health actions. From 2015 to 2018, less than R$37M (circa £7.5M) was specifically allocated to the health sector for the treatment and diagnosis of children affected by the syndrome.[18] At the beginning of 2018, the Ministry of Social Development transferred R$2.4M to co-finance day-care centres[19] in ten municipalities for affected children, but this was the only budget allocated to the social assistance field. The expenditure cap is considered a real threat to health and social protection systems, as the policies and programmes will not be able to fulfil their most basic objectives in the next decades within such a strict limit (Vieira *et al.* 2017; Paiva *et al.* 2017).

4.2 Epidemic outbreak narrative

The policy responses by the Federal Government, mostly from high-level decision-makers at the Ministry of Health, the Presidency of the Republic, and the WHO were framed within an 'outbreak narrative'. According to Wald, this narrative 'begins with the identification of an emerging infection, includes discussion of the global networks through which it travels and chronicles the epidemiological work that ends with its containment' (2008: 2). The Zika

17 http://g1.globo.com/rs/rio-grande-do-sul/noticia/2016/05/ministro-do-desenvolvimento-social-preve-pente-fino-no-bolsa-familia.html

18 This value corresponds to the sum of R$10M allocated through the Rapid Response Strategy and R$27M through the Ministerial Ordinance 3502/2017, that transfers resources to SUS units in municipalities for the diagnosis and treatment of children with microcephaly. The values were calculated based on the average exchange rate in August 2018.

19 Centros-Dia are public facilities from the social assistance sector that assist people with disability and their families. In the beginning of 2018, the Ministry of Social Development announced the building of 11 centres for children with microcephaly and other severe neurological diseases. http://mds.gov.br/assuntos/assistencia-social/unidades-de-atendimento/centro-dia

epidemic is presented in official discourses as having a clear beginning, a middle, and an end: it had broken out in the Northeast, required coordination efforts to combat spreading, and was successfully contained by the Brazilian government.

This view, however, obscures the social, political, economic, and technological dynamics that occurred before and after the official timeline defined by the outbreak narrative. In the case of the Zika virus, this narrative cast aside the intersecting inequalities that allowed the epidemic to spread, such as the inadequate access to health and sanitation, poor living conditions, precarious urban development, the history of neglect of public policies that combat the vector, and the lack of reproductive rights (Diniz 2016). The narrative also presented the epidemic as located within the geographic boundaries of the Northeast, ignoring the other states that were highly affected by the epidemic – Rio, for example, had the third highest number of confirmed cases, but was not considered a 'priority' state by the Federal Government nor it was under media spotlights.

In addition, the declaration of the 'end' of the epidemic, through the withdrawal of both national and international health emergency status,[20] disregarded the long-term socioeconomic, health, and emotional impacts of the disease, as well as the yet unknown consequences in infected children's development (Henriques 2017; Avelino-Silva and Kallas 2018).

4.3 Mosquito-centred narrative

When the first studies pointed to a correlation between microcephaly and the Zika virus in November 2015 (FIOCRUZ 2015), state bureaucracies rapidly sought to draft responses to the crisis, focusing mostly on the control of the *aedes* mosquito*.* The government promoted awareness campaigns that urged individual and communities to eliminate of breeding sites, increase inspections of buildings and households, and invest in biotechnical solutions to eradicate the vector and to avoid mosquito bites. A National Office of Coordination and Control was installed to monitor actions in this area, involving different sectors of the government, such as defence, health, education, and social assistance. Subnational offices were replicated in all states of Brazil and 1,769 municipalities by the end of 2016 (Ministério da Saúde 2016). Most of the extra budget for Zika-related actions was allocated to the purchase of mosquito repellents and to the armed forces, for conducting inspections and providing support for the transport of agents and communication.[21] Due to bureaucracy problems, repellents were only delivered to the mothers at the end of 2017, two years after the outbreak of the epidemic.

As most of the public efforts were concentrated in the fight against the vector, critics of governmental response consider the official action 'mosquito-centred' rather than human sensitive (Diniz 2016; HRW 2017). The logic of campaign awareness shared the responsibility of the epidemic with individuals and communities, imposing the responsibility of the control of the vector on citizens and connecting individual non-compliance to the disease consequences (Soares 2017). This framework had permeated previous efforts dealing with other arboviruses, through sanitary campaigns that 'focused on the mosquito and forgot the people who live in the mosquito-filled area' (Löwy 2017: 522). Not only has this narrative ignored government responsibilities in providing sanitation, infrastructure, and waste

20 The World Health Organization ended the declaration of Public Health Emergency of International Concern for Zika in 18 November 2016, while the Brazilian Ministry of Health withdrew the status of Event in Public Health of National Concern in 11 May 2017

21 Concerning budget allocation, most of these activities were implemented under existing budget lines and programmes (e.g., the national programme for dengue). An executive decree authorized R$420M (circa £84M) to Zika-related activities, divided into four main parts: R$300M for the purchase of mosquito repellents; R$70M for the armed forces, to conduct inspections and provide support for transport of agents and communication; R$50M for research and the rest as a contingency fund. Later, R$37M was allocated to the health system for diagnosis and rehabilitation treatments.

management; it has also driven the attention away from the health and social needs of those most affected by the epidemic.

4.4 Social protection narratives

Finally, the joint responses from the Ministry of Health and Ministry of Social Development were framed around a recognition that the Zika epidemic affected mostly poor and vulnerable populations. As I heard from a coordinator of the Brazilian Ministry of Social Development (Ministério do Desenvolvimento Social – MDS), the social risks and vulnerability imposed by the disease classified those families as the 'targeted group of social assistance policies'. Besides, the disabilities caused by SCZ included the children as potential beneficiaries of the BPC, what would imply extra demand to the social assistance and social security units to locate and registry these families in the social programmes they were entitled to. The SUAS network also demanded for its presence in the territory, which would allow for the spread of awareness campaigns in poor areas as well as the identification of suspected cases and their reference to health units.

In spite of this, the narrative presented by the MDS framed the social protection responses to the syndrome in terms of inclusion of the affected population in existing social policies, instead of creating or adapting new policies or actions. The eligibility criteria for social benefits were strictly maintained, while access was hampered by controlling and targeting measurements, as mentioned above. Despite giving priority to the assistance of children with microcephaly and establishing administrative procedures to ease their access, the income criteria of BPC and PBF remained inflexible, not considering the increasing expenses of medicines and treatment. The Ministry has justified their actions by saying that 'people with disabilities' are an indivisible group and there is no bespoke assistance to people with different disabilities, as they all have extra costs involving health treatments. According to the MDS, an exception for children with microcephaly would violate the principle of isonomy in the concession of the benefit (Ministério do Desenvolvimento Social 2017). As I discuss in section 6, this notion contradicts the subnational narratives on the demands and material needs of the affected population.

These national narratives and institutional frameworks directly shaped the scope of agency and policy spaces for subnational actors. In the context of SUAS, the decisions were centralised at the national level, although validated through several participation mechanisms. Hence, the ability of states and municipalities to innovate was limited in the social assistance governance, mostly when compared to the SUS organisation (Coelho and Shankland 2011). In the following sections, I present the context of the state of Rio de Janeiro and the subnational narratives at both state and municipal level that have framed the social protection responses to the Zika epidemic in the state.

5 The context of Rio de Janeiro

At first glance, the scenery of Rio de Janeiro differs significantly from the semi-arid region of the northeast of Brazil, the geographic centre of the Zika epidemic outbreak. While the northeast is depicted in the national imaginary as a problem region for its natural and socioeconomic conditions[22] (Albuquerque Junior 1994), Rio is in the southeast, the wealthiest and most industrialised region in the country. Its capital is the main touristic destination in Brazil, with beautiful natural and urban sceneries. On the other hand, the city is

22 The northeast is the poorest and most unequal region in Brazil and the least urban region in the country (IBGE 2014). The 'sertão' – dry highlands – where the first cases of microcephaly were notified in 2015, has historically been portrayed in the media and literature as a miserable region, devastated by droughts and extreme poverty. This view blames natural characteristics and local management, while neglecting structural reasons, discursive and non-discursive practices that constituted the 'northeast' as problematic (Albuquerque Junior 1994)

known for its contrasting landscape and visible inequalities, where *favelas*[23] and luxury buildings are side-by-side and where violence derived from drug trafficking is a routine part of life for most of its population.

The state of Rio de Janeiro has a population of 16.7 million people, the third highest in the country.[24] It is considered a wealthy and urban state, with the second highest GDP (11 per cent of the national economy), the fourth highest Human Development Index, and a household income 25 per cent higher than the national level (IBGE 2017). The state is the country's biggest oil producer, accounting for more than two-thirds of the national production (ANP 2018). Since 2008, when petroleum and natural gas reserves were discovered, the state has increased its spending on public services and investments, doubling its expenditure from 2010 to 2016.[25]

From 2015 to 2016, Rio de Janeiro faced an unprecedented fiscal crisis, due to a sharp drop in income from state taxes, central government transfers, and oil royalties. A combination of factors resulted in this scenario: national recession, that impacted tax revenues; a fall in oil prices (from US$110.00 a barrel in 2014 to US$40.00 in 2015); corruption scandals involving the Brazilian Petroleum Corporation – Petrobras; high expenses related to the organisation of the Olympic Games; and years of public finance mismanagement.[26] The state declared 'public calamity' over finances in June 2016, when the deficit reached US$5.5 bn.

The crisis had a considerable impact on health, security, education, and social assistance services. In December 2015, the governor declared a state of health emergency as the budget shortfall caused a crisis in the healthcare system. When the Zika epidemic reached the state in 2016, a chaotic outlook was established: civil servant's salaries were delayed for months; public units ran out of equipment and supplies; and strikes erupted in many cities. In addition, the lack of personnel was intensified due to a wave of retirements driven by fears of the reform in pensions schemes, as announced by the central government.

In this context, Zika was one among many other problems that afflicted the state in 2016. The first cases were confirmed at the beginning of the year and reached their peak a few months later.[27] At that time, governmental efforts were focused on the control of the vector, in order to prove that Rio de Janeiro was a safe place to host the Olympic Games. Meanwhile, health sector services were coping with high and complex demands of epidemiological notifications, diagnosis, and therapeutic treatment of children born with microcephaly and other neurological disturbances, while working with very limited budget, resources, and staff.

As the games ended and the national health emergency status was lifted, the Zika epidemic in Rio de Janeiro was set aside by the media and the national government. By the end of 2018, Rio de Janeiro had the third highest number of confirmed cases of microcephaly in Brazil: 290 confirmed cases out of 1,117 notified (MS 2018). Since 2016, the State Health Secretariat has established information flows, protocols, and procedures for patient reference and monitoring; defined centres for neurological exams and diagnosis, rehabilitation, and therapeutic care; trained primary care agents and professionals; and is striving to help local health facilities to attend to the families in their territory.

23 Brazilian word for slums, informal urban settlements.

24 The population of Rio de Janeiro accounts for 8.4 per cent of inhabitants in the national territory and is the second most densely populated in Brazil. In addition, 97 per cent of its population live in urban areas. https://cidades.ibge.gov.br/brasil/rj/panorama

25 www.dw.com/pt-br/como-o-estado-do-rio-de-janeiro-chegou-%C3%A0-fal%C3%AAncia/a-19344065

26 Besides accusing a deviation of US$21bn in Petrobras, the 'Operation Car Wash' – a national effort to investigate corruption allegations – also charged three former governors for corruption and money laundering.

27 Governo do Estado do Rio de Janeiro (2018).

For instance, the social assistance sector was involved in the design of the state responses to the epidemic in 2016, but institutional changes and budget constraints interrupted the planning of actions at the state level. Coordination between the health and social assistance sector was re-established in 2018 to elaborate a plan of action addressing the consequences of Zika, following the conditions set by the central government. In the next section, I present the actors involved in the construction of this response and their narratives about the dilemmas, constraints, and individual agency involved in this process.

6 Subnational policy narratives and actors

When the first cases of Zika virus infection-related microcephaly were confirmed in Rio de Janeiro, the epidemic had already broken out in the Northeast. The southeast region was mostly affected in the second wave of the epidemic (Oliveira *et al.* 2017), reaching its peak in the first semester of 2016. By that time, there was already scientific evidence on the link between the rise of microcephaly cases and the Zika virus. Also, the national government had launched the National Plan and most of the protocols and instructions for the health and social assistance systems. For this reason, the reorganisation of services at the state and municipal levels to assist the population with the syndrome was largely built in reaction to the national policies and guidelines.

What was the response of the state of Rio de Janeiro to the social consequences of the Zika epidemic? If we consider the narrow concept of policies, which sees policy as a linear, problem-solving process, where the decisions are registered into documents, little was done. The state health and social assistance sectors launched a joint technical note in June 2016 with guidelines for the municipalities[28] and a state plan to address SCZ were negotiated among these sectors in 2018.[29] At the municipal level, there were no specific instructions or actions targeted at the population. However, this paper shares the assumption that policy is also performed during routine interactions, being enacted by the agency, network, and practices of bureaucrats and practitioners. In this regard, a broader view of the policy process should be adopted to understand the social protection response to the Zika epidemic in the state of Rio de Janeiro.

6.1 Those who build the response: actors and networks

The actors involved in the formulation of a social protection response in Rio de Janeiro resemble the national institutional structure and can be organised into three main sectors: social assistance, social security, and health. While I chose not to focus my analysis on the health sector, it was not possible to dissociate it from the social protection policies. This is because the state response involved integrated actions from both areas at the mid and local level.[30] Below, I list some of the institutional actors involved in the making and delivering of social policies to the virus-affected population. The list is not intended to be exhaustive, but to present those that work 'in between', as mediators of state-citizen relations (Lipsky, 1980) or between national and local levels.

28 The Technical Note established communication flows, reaffirmed the need to include the affected population in the existing policies and recommended the intersectoral coordination of both areas (Governo do Estado do Rio de Janeiro 2016).

29 The Plan was coordinated by the Health Secretariat and involved representatives from the social assistance sector. The plan not yet launched when this paper was written (August 2018), but interviewees alleged that it has addressed both health and social consequences of the syndrome.

30 For most cases (or at least in the ideal path prescribed by the national government), the social assistance sector is activated by local health units when a suspect case is notified. At the same time, public hospitals and diagnostic centres have social assistance teams that inform and assist the families in accessing social benefits.

- Social Assistance: State Secretariat of Social Assistance and Human Rights;[31] Municipal Secretariat for Social Assistance and Human Rights; CRAS (local social assistance centres); and the SUAS network.
- Social Security: state units of the INSS.
- Health: State Secretariat of Health (mostly the primary care and epidemiological surveillance sector); SUS; and two reference centres that were designated to attend to the population with SCZ: Fernandes Figueira Institute, a clinical and research centre that conducts rehabilitation therapies; and the Brain Institute, a neurosurgical centre responsible for diagnosis analysis.[32]

Mothers' associations were active in using legal rights-claiming strategies to demand state action in the health sector. However, I was unable to identify evidence of their presence in the existing institutional participatory spaces of mid-level bureaucracy for shaping the social policy response.[33] It is worth highlighting that this fact does not allow for the conclusion that these policies were built up in isolation from those affected by the epidemic. Despite the absence of these groups in most of the official decision-making processes, the daily interactions between the families and frontline workers shapes and considerably influences the enactment of policies at the local level.

6.2 Those who told the stories: interviewed actors

Before proceeding to the narrative analysis, it is crucial to mention who the actors were 'behind the stories' of the social protection policy response to the Zika epidemic in Rio de Janeiro. Although the small number of interviews does not allow for generalisations, the diversity of the respondents' positions and institutional affiliations offers a wide overview of the multiple stages of the policy process.

Over two weeks, I interviewed bureaucrats and frontline workers from the state and municipal level. They work in the health, social assistance, or social security sectors. From the ten actors interviewed, nine were women – most of them in their thirties or forties.[34] Four were mid-level bureaucrats, working in offices, with occasional encounters with practitioners or citizens. Six could fit into the category of 'street-level bureaucrats' since their work involved daily interaction with citizens and beneficiaries. However, all the mid-level bureaucrats had previously worked as frontline practitioners. There were eight social workers, one doctor, and one nurse. Four of them were employed by the state of Rio de Janeiro, one by a social assistance NGO, and three by the municipality of Rio de Janeiro.[35]

In the following part, I present some of the narratives and stories brought up during the interviews. These narratives were not necessarily presented linearly by the interviewees, nor were all the elements mentioned by all, although they were referred to in most of the conversations.

31 In 2018, this Secretariat was restructured and incorporated into the Science and Technology Secretary. Its current name is State Secretariat of Science, Technology, Innovation and Social Development.

32 These two institutions have a social service team that assists the patients.

33 Some NGOs were involved in assisting the affected population, although this refers to some occasional situations. For example, in the formulation of the State Plan, the NGO Zika Movement was consulted, and the NGO Rio Solidário provides transportation to patients in some cases, when required by the municipalities.

34 For reasons of confidentiality, I decided not to present the information of each interviewee separately.

35 The interviewees' institutional affiliations were the Fernandes Figueira Institute, a research institute and rehabilitation centre for children with disabilities; the Brain Institute, responsible for diagnosis; the NGO Rio Solidário; the state Secretariat of Science, Technology and Social Development; the state Secretariat of Health; the municipal Secretariat of Social Assistance and Human Rights, and the National Institute of Social Security.

6.3 Policy narratives: making policies in adverse circumstances

By assuming that narratives are one way of telling a story and framing a particular problem, and are 'stories with purposes and consequences' (Leach and Dry 2010: 6), I consider the narratives built during the interviews as more than accounts of reality from state officials and frontline workers. Rather, they shaped policy responses towards the Zika epidemic in the state of Rio de Janeiro, be it through widening or by accepting – and working within – the limits of policy spaces imposed by national responses and by the local context. In this regard, the fiscal crisis and the national response give context for these subnational actors: they do not attempt to challenge those assumptions, but to act within their bounds, while finding gaps and breaches for action.

On these lines, I opt for presenting the narratives in four main sets that might be complementary, conflicting, or sometimes overlapping.

6.3.1 State collapse narrative: 'There are no social protection policies in Rio'

The fiscal crisis in the state and its impact on the social assistance sector was highlighted in all interviews, but with different nuances. On the one hand, a more sceptical narrative claimed that there were no social policies in Rio de Janeiro targeted at the population with SCZ. On the other hand, the interviewees emphasised the adverse, chaotic context in which the epidemic emerged and the strains it imposed on the already scarce human and financial resources in the health and social assistance units.

Three underlying reasons might have influenced the first view: (1) Only one official instruction – namely, the joint technical note – was produced by the state secretariat for social assistance by 2018; (2) The secretariat was downgraded 2017: due to lack of budget, the secretariat was reduced to seven employees and was incorporated into the science and technology sector; (3) The lack of flexibility and innovations from the Federal Government led to the idea that nothing 'new' was created or adapted for the virus-affected population. As mentioned by one social worker: 'You will be disappointed when finding that there are no social policies in Rio for these families.'[36]

Other interviewees highlighted the lack of resources and staff caused by the fiscal crisis in Rio de Janeiro and its consequences for working conditions and the delivery of services to the affected population. The social assistance and health teams had to adapt their routines in order to meet the increasing and complex demands of the epidemic, with a reduced budget and workforce. The local units lost personnel, salaries were delayed, and there was no physical space to attend the population, nor budget for transportation of staff and materials. A social assistance worker at a health unit said:

> *The challenge was to restructure the services in a very adverse circumstance. Despite the national crisis, Rio was witnessing a dark moment: many public employees were not receiving their salaries; there were lots of strikes. This had affected public services, health assistance, social benefits. For example, many registration units for social benefits and pension schemes were closed. Senior professionals were retiring, so there were not staff to assist this huge demand that was emerging.*

In this regard, the interviewees share the opinion that assistance to the population fell short on what should have been an effective, rapid, and just response. The epidemic imposed extra work and the reorganisation of services, which was handled through the engagement and agency of practitioners and bureaucrats.

36 The interviews were conducted in Portuguese, transcribed and translated by the author.

6.3.2 Vulnerability and gender narratives: The imperative for action

During the interviews, the socioeconomic conditions of the affected families, the extra and unequal burden imposed on mothers by care responsibilities and the social risks resulting from the disease were evident in all the conversations. Even among those who did not work on the frontline, the consequences of the syndrome were perceived as a sensitive issue, with severe impacts for the children and their caretakers which required urgent action.

The interviewees were aware that the epidemic victimised mostly poor and marginalised women, who tend to be the responsible for children's care. They also recognised the social, economic and emotional consequences imposed by the disease on the mothers, such as the high cost of medicines, time-consuming rehabilitation treatments, and the lack of information about future effects of the syndrome. Caretaking demands overwhelmed mothers, who were often full-time carers to children with severe disabilities. Sometimes they were abandoned by their husbands and relatives or stigmatised by the community. These women constantly dealt with frontline workers in their daily struggles to access services, adequate treatment, and answers to questions that science has yet to find.

Hence, in the interviews, the notion of *vulnerability* was related to gender roles, disabilities, and inequalities. This notion was constantly mentioned as a two-way process: while the Zika virus has mostly affected vulnerable women and families, the fact that it has generated disabilities has also deepened their vulnerability and social risks. In this regard, *vulnerability* was understood as more than economic deprivation, but also as a broader facet affected by gender, living conditions, cultural practices, and community relations.

These multiple vulnerabilities allowed affected families to classify as the target population for 'social assistance', and justified the mobilisation of the social assistance network. However, the former understanding of vulnerability conflicts with the Federal Government's classification of who can access social benefits, which is based on strict and inflexible income criteria. As said by a social assistance worker that had been in the administrative sphere during the outbreak:

> *Social assistance deals with social vulnerability and risks. We cannot consider that these factors are only related to income. It involves emotional ties, social relations, access to public services. Regardless of the income, it is a Syndrome that will change the routine of the families. The vulnerability of these families was intensified by some issues that they still did not know how to handle: a child with disability, a mother that had to leave her job for her caring duties, sometimes the separation of parents – because the men could not hold on… the lack of acceptance by the community, the mothers loss of their access to participatory spaces, as they are excluded by groups or exclude themselves, because they do not have time, they devote a lot of their time to the child.*

Finally, the fact that nine of the ten interviewees were women is noteworthy. This resembles the gendered division in the social assistance and primary care sectors in Brazil. Although it was not possible to identify a 'solidarity' discourse, some interviewees mentioned empathy as a driving force that compelled them into action, despite the adverse conditions. As said by a bureaucrat: 'Despite professional reasons, there was the personal side. I had a child few months before the outbreak, I knew what they were passing through'.

However, it is also worth mentioning that issues concerning reproductive rights and abortion were only brought up when I explicitly asked, reaffirming the invisibility of these issues in national and local policy narratives and responses.

6.3.3 Reality-gap narratives: 'Our reality is much worse'

There was a shared perception that some policies and instructions from the Federal Government were delayed or inadequate in addressing the complexities of SCZ. The interviewees pointed out some decisions that were distant from the real-life circumstances of the affected population, decisions that might have hindered an adequate social protection response. As said by a neurologist:

> *The high-level decisions were delayed. The Ministry of Health was asking us to reconduct some exams in already diagnosed children. They did not know what they were doing, cause the Ministry is not at the frontline, assisting the child. We are the ones who are here, seeing, assisting the children, and I would not submit them to this extra and unnecessary suffering.*

In addition, it was alleged that instructions provided by the MDS were based on an idealised pathway towards a social assistance system that was inconsistent with the reality of the local units (CRAS) and municipal teams. Working conditions, material resources, human capital, and infrastructure varied in each municipality and, in the case of Rio de Janeiro, were harshly constrained by the crisis. Quoting a frontline worker from a health unit:

> *The ministerial ordinances were very beautiful in theory. In practice, the social assistance centres in the state of Rio had a lot of problems, of all kind: human resources, financial, equipment'. Another bureaucrat mentioned: 'When the prescribed flow works, the cases are referred to the health and social assistance units, and they schedule appointments to social benefits registration. But you know, some CRAS do not even have telephones.*

Two examples of top-down decisions criticised by the interviewees within this narrative are worth mentioning: the withdrawal of the status of Emergency in Public Health of National Concern (Emergência em Saúde Pública de Importância Nacional – ESPIN); and new bureaucratic requirements to register the general population for social benefits. According to the interviewees, the withdrawal of the ESPIN ignored the long-term effects of the epidemic and deviated public attention and budget allocation. As mentioned by a social assistance at a health unit:

> *The demobilization at the national level was very bad. We lost political strength, we lost resources. Every day I am under pressure to close the ambulatory, to reduce its opening times, because 'there is not Zika anymore, it is over'. You have to prove to people that it is not over.*

This was also apparent in a mid-level bureaucrat discourse: 'After the withdrawal of the ESPIN, I faced even more difficulties. The public officers do not understand the priority. The number of affected children is not that high, but the consequences for their lives are huge'.

Furthermore, changes in social programmes' regulation – following the orientation of the central government after the presidential impeachment – created new mandatory procedures which hampered access to social security benefits for the families As mentioned by one INSS worker, a person goes to the INSS office four to ten times to deal with bureaucratic requirements before receiving the benefit. This is time-consuming, imposes high transportation costs, and is incompatible with many families' living conditions. The mandatory registration in the Single Registry (CadÚnico) for all BPC beneficiaries, established in 2016, is mentioned in most interviews as undermining the access of affected families to the social benefits to which they are entitled: 'Despite INSS agencies, they have to go to social assistance units to register for CadÚnico. This creates a longer way to access public policies and requires time and money for transportation.'

6.3.4 Agency narrative: 'We do what is possible'

According to the interviewees, the fiscal crisis scenario, the austerity discourse and budget cuts, and the officially declared end of the epidemic left little room for manoeuvre to meet the needs of the virus-affected population. Local health and social assistance units were suddenly hit with demands to assist children with disabilities and social vulnerabilities that exceeded their institutional capacities and responsibilities. 'It was a desperate situation. We thought: how are we going to assist these people, right now, in this chaos? We had to do some juggling' – mentioned a social worker.

In spite of these challenges, the interviewees highlighted individual and collective initiatives at different levels in policymaking and implementation to cope with this new demand. Mid-level bureaucrats reported having limited powers of discretion to set the agenda, through convincing their superiors, reallocating budget, finding cheaper solutions, and maintaining the discussions within technical areas. As said by a bureaucrat:

> *I decided to lead this discussion. It is a priority in my agenda. The resources sent by the Ministry of Health were among the few ones we had received, so this helped me to convince my superiors that Zika was a priority topic.*

The option for a joint technical note to instruct the municipalities, instead of an ordinance, was based on the interviewed bureaucrats' impression that the debate would be blocked or set aside if conducted at high-level decision-making. In addition, most of the meetings, instruction, and training of municipal teams were conducted virtually instead of face-to-face, to avoid travel expenses. As said by a bureaucrat from the social assistance sector: 'Our orientation to the municipalities was compromised: we had planned many local visits, but we could not do it because we did not have cars or fuel. So, we had to do all the monitoring through virtual means.'

Besides, the interviewed mid-level bureaucrats maintained that their engagement with Zika-related topics was more a personal endeavour than an institutional one. 'It was an issue that I had identified as my own responsibility' – said a bureaucrat from the health sector. When talking about the coordination among different areas, another bureaucrat mentioned: 'When we decided to begin the conversations between the health and social assistance sectors, it was not a request from our superiors. It was our own initiative. It was a commitment from the technical sectors'.

At the frontline level, workers from the health and social assistance units established personal networks to better instruct families and ease their access to social benefits. Some actions went beyond their assigned responsibilities, institutional roles, and working hours. For example, the interviewees mentioned providing their personal contact information to the mothers; helping with appointments, documentation, and requirements; creating informal networks among colleagues to prioritise access to services; and providing emotional and psychological support – even when this was beyond their assigned responsibilities. As said by a social assistant at a hospital:

> *Our team is reduced. We orient the families about their rights and refer them to the social assistance institutions. It is not our role to monitor whether they were able to access the services. But this distressed us, because we know that they will have difficulties to access nurseries, receive the social benefits, primary care, etc. So sometimes we call the CRAS, we call the guardianship council, we monitor them as far as possible… this creates an extra demand for work. We were not paid extra hours, we did not receive any extra budget. There are a lot of issues beyond the medical care, and this weights a lot to us.*

Since their position involves daily encounters with the affected population, street-level bureaucrats became sensitised and developed personal ties with the families: 'When you see these women and think about the consequences to them, all the constraints they will face, the lack of resources, lack of access, lack of response. It is very difficult,' said the same social assistant. He/She also said, 'We have to be activists, make some noise, so they can listen to us at the superior stances. They say it is not a problem anymore, but we know it is not over.' With limited staff and material resources, the social protection response in Rio de Janeiro was highly dependent on the individual agency of bureaucrats and frontline workers and built through extra hours of work, creative action, and emotional involvement.

7 Some conclusions

As the previous sections have shown, the policy processes involving a social protection response to the SCZ in Brazil are undoubtedly complex. They are built through multiple interactions between actors, discourses, knowledge, and interests that do not fit within rational, linear policy models. Thus, an approach that favours the fluidity, contingency, and messiness of policy process (Shore 2013; Scoones *et al.* 2006) is crucial to understand the multiple and complex realities that are embedded in the state responses to the Zika epidemic.

From the first medical observation that linked the Zika virus with microcephaly in 2015 to the moment an affected child is seen by the state and included in its social protection network, a multitude of variables intervene and shape the response pathway. In this sense, although this paper left aside other important aspects and discourses regarding SCZ, the narratives presented here provide an account of the contradictions, dilemmas, and roles that frame state responses to epidemics in the context of crisis.

At the national level, dominant narratives tend to 'close down' the policy space for action (Leach *et al.* 2010), framing SCZ through narratives that justify austerity measures and present the syndrome as a controlled epidemic within a specific time and space. These narratives led to a state response which privileged short-term, mosquito-centred solutions, while sharing the responsibility of the syndrome with those most exposed to the vector. Besides, although the vulnerabilities of the affected population were acknowledged, the social protection response at the national level was framed as a matter of inclusion in existing policies, ignoring the singularities of the syndrome and the extra unpaid care demands it imposes on poor women.

The agency role of subnational mid-level bureaucrats and frontline workers is what composes, in practice, a social protection response to the Zika epidemic. These mediators are *de-facto* policymakers (Goetz 1997). They work 'in-between' the dichotomies of national-local, state-citizen, decision-implementation, political-technical, finding breaches and stretching the boundaries of policy spaces imposed by the national narratives and the crisis contexts. In the state of Rio de Janeiro, these actors are mainly women that, driven by professional ethics, political motivation, or a sense of affection and empathy, build epidemic response pathways through a succession of small wins (Eyben 2013) within a very narrow policy space.

On this point, the underlying narratives of the social protection response to SCZ in Brazil point to the necessity of 'opening up' governance approaches to epidemics (Leach *et al.* 2010) that embrace strategies of resilience and innovation by mid-level and frontline bureaucrats. The case of Rio de Janeiro indicates that social policy responses to epidemics can be enacted even in adverse and chaotic circumstances, but they rely on informal networks and individual motivations, agency, and discretion of mid-level and frontline

workers. The sustainability of these policies depends on the will, incentives, and autonomy of these individuals and, thus, policies are vulnerable to political changes that might affect their position within institutions.

‘Our lives have completely changed after Zika’ – said Dr. Celina Turchi, the epidemiologist who found the evidence of the association between the Zika virus and microcephaly in Brazil, in the Seminar ‘Social Innovation and Experiences in Health Surveillance’, which I attended in Recife in June 2018. Similar quotes were repeated during the interviews by bureaucrats and frontline workers that did not succumb to the ‘taken-for-granted’ (Eyben 2013). The Zika epidemic imposed an unequal and heavy burden on poor women’s shoulders, who embodied the inequalities, negligence, and violence perpetrated by a state that tried to silence their voices. However, the recognition that their lives ‘have completely changed’ also drove other women to change their lives, attitudes, and routines at work to support and echo these voices. In the case analysed in this study, the social protection response was made by women for women.

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