

POLICIES TO COMBAT THE COVID-19
PANDEMIC, HEALTH DEMOCRACY
AND THE RIGHT TO HEALTH

*POLÍTICAS DE COMBATE À PANDEMIA DA COVID-19,
DEMOCRACIA SANITÁRIA E DIREITO À SAÚDE*

*POLÍTICAS PARA COMBATIR LA PANDEMIA
COVID-19, LA DEMOCRACIA DE LA
SALUD Y EL DERECHO A LA SALUD*

*Sayonara LEAL**
*Marko MONTEIRO***

Introduction

This dossier focuses on the discussion of pandemic response policies in different countries, guided by the normative principles of sanitary democracy and the right to health. It aims to explore various aspects of Brazil's response to COVID-19, particularly those related to democracy, science, and the principles of the Unified Health System (SUS), with the goal of investigating the lessons we can draw from that emergency period. Despite the extensive literature produced on COVID-19, especially during the height of the health crisis, we believe there is still much reflection needed on how Brazil addressed the greatest health crisis of the 21st century: how can we understand the successes and failures in managing COVID-19? How should we prepare for future emergencies, which will inevitably arise? To what

* Associate Professor, Department of Sociology, University of Brasília (UnB). Postdoctoral Fellow in Innovation Sociology – *Centre de Sociologie de l'Innovation*, École des Mines de Paris, France. Doctoral degree in Sociology (UnB), Master's degrees in Social Change (ULille) and Culture and Communication (UnB), and Bachelor's degree in Journalism (UFS). Orcid: <https://orcid.org/0000-0001-9369-1960>. Contact: sayoleal@gmail.com.

** Associate Professor, Department of Scientific and Technological Policy, State University of Campinas (UNICAMP), SP, Brazil. Doctoral degree in Social Sciences. Orcid Link: <https://orcid.org/0000-0003-4008-4985>. Contact: carambol@unicamp.br.

extent can the pillars of SUS and its participatory and democratic tradition provide solutions for crises like these, and how can we protect this legacy?

In the case of Brazil, we encounter an emblematic situation where scientists, experts, and public health activists were largely excluded from the decision-making processes led by the Executive (Castro *et al.*, 2024), which could have adopted measures more aligned with the needs of managing the health crisis (Abrucio, 2020; Campos, 2020). The consequences of the lack of expert advice are numerous and help explain the results considered disastrous by many specialists. To summarize, this includes the disconnection between federal guidelines and those of the World Health Organization (WHO) regarding prevention, combating the spread of the new coronavirus, and the delay in mass immunization.

The disjunction between science and public crisis management (Alves *et al.*, 2023) also discouraged commitment to collective health as a common good in the face of the global pandemic. Beyond Brazil, in several other countries, we observed devastating effects of the pandemic in terms of widening social inequalities among already vulnerable populations (Fabrin *et al.*, 2023; Silva, Silva, 2023), as well as gestures of repudiation towards social isolation measures and vaccination against COVID-19.

In light of the complex phenomena associated with the pandemic, this dossier will address the following reflections: 1) the discursive links between denialist rhetoric and its connections with the contemporary political scene marked by the rise of the extreme right, including the use of Internet memes in the agitation of propagandists of fake news in the online public sphere concerning disease containment measures; 2) the governance of science and technology and the problematic relationship between politics and expertise; 3) the relationship between right-wing government policies and gender and racial inequalities during pandemic times; 4) government incentives for science and technology policies for producing knowledge about the coronavirus in different countries; 5) the hermeneutic critique of sensitivity policies and the associated emotional ecologies, enabling an analysis of the possibilities for restructuring collective health in the wake of the COVID-19 pandemic.

Response to Covid: Science and Public Health Democracy

The COVID-19 pandemic has placed us at the crossroads between public health democracy, the right to health, and the implementation of evidence-based pandemic response policies. Public health democracy is a dynamic concept because it refers to ongoing democratic practices in health that involve various stakeholders, including governments, medical professionals, policymakers, and citizens (patients). Initially, it can be defined as “an approach aimed at involving all stakeholders in the

health system in the development and implementation of health policies, in a spirit of dialogue and consultation,” also resulting in the recognition and promotion of the rights of users of the health system (ARS, 2022). This minimal definition points to the need to inform and involve different publics in the formulation of public policies, fostering the alliance between medical-scientific expertise and the social experience of citizens affected directly or indirectly by diseases. Health democracy can also refer to practices that start between a patient and a doctor, where the doctor considers the patient’s capacity to participate in their treatment (Arveiller, Tizon, 2016), as well as to the obligation of democratic state entities to provide services and information about diseases and health care to the population.

Social Studies of Science and Technology (STS), for example, have extensively highlighted cases and reflections on the developments in open science, emphasizing movements towards democratizing access to scientific knowledge and involving both lay and expert audiences in the production of scientific knowledge and the formulation of public health policies (Chilvers, Kearnes, 2020; Epstein, 1995). here is an ongoing debate in this field about the need to expand forms of public engagement in science, promote greater participation of laypeople and other publics in technical deliberations, and reject the inevitability of technocratic governance of health and environmental issues, among others. The research agenda in Science, Technology, and Society (STS) thus underscores the necessity of conducting science in democratic contexts, where questioning and dialoguing with technoscientific authorities is normatively allowed through mechanisms of participation and public consultations on matters of life (Epstein, 2023; Turnhout *et al.*, 2020. However, this does not mean tolerating denialism that endangers collective life and well-being, as such denialism is unjustifiable under these terms.

Knowledge about vaccines or climate change produced by expert systems should not be questioned based on authoritarian populism and eugenic appeals, as was the case at various points during the pandemic. We believe that science and expertise hold an important place in contemporary democracies and are part of continually improving deliberative processes. As Forst (2023:7) explains, “considering such truths does not pre-determine how to answer the question of which ecological policies should be implemented and by whom,” or which vaccines should be adopted. This is precisely what needs to be debated. Democracy is the political regime where we can assert the epistemic right to truth, regardless of the context, especially when access to accurate information can preserve lives.

In situations of emerging health crises, such as the COVID-19 pandemic, the achievements of public health democracy are often compromised, as the crisis did not favor the development of shared decision-making models (Bergeron, 2022). During the coronavirus pandemic, “irresponsibilities” multiplied concerning how technical decisions or decisions based on expertise were made (Epstein, 1995;

Monteiro, Shelley-Egan, Dratwa, 2017). Public health democracy relates to the functioning of consultative and deliberative bodies in the health sector (conferences, public consultations, councils), as well as Observatories and other collectives, and the development of applications by civil initiatives aimed at disseminating reliable information about diseases and their epidemics, especially during times of rapid proliferation of infodemia¹ (Balakrishnan *et al.*, 2022; Freire *et al.*, 2023). However, during pandemics, a minimal level of health democracy is maintained when the epistemic right to accurate sanitary information from government sources is guaranteed to citizens, along with measures based on expertise to mitigate the spread of the disease.

We know that the COVID-19 pandemic led public authorities worldwide to adopt exceptional health measures and promulgate regulations to legally address the urgent situation posed by the spread of the new coronavirus. In this context, the establishment of mixed consultative bodies capable of advising governments on informed decision-making based on internationally and locally generated technoscientific data becomes relevant. This also involves engaging existing civil society organizations, which are consultative and deliberative in nature, and providing specific expertise and robust knowledge about the manifestation of the pandemic at the local level, particularly, among vulnerable populations. The engagement of the Executive Branch with civil society entities on health issues informs public policies that better align with the needs of combating disease proliferation, as these bodies demonstrate the ability to understand, interpret, and shed light on the expectations of these territories and populations.

In this context, the management of the Brazilian Executive during the pandemic was emblematic, as both scientists and public health experts and activists were excluded from the decision-making processes led by the federal government, which failed to adopt measures more aligned with the need to address the health crisis. In Brazil, a series of collectives and independent civil society bodies, comprising both experts (scientists) and non-scientists, mobilized to counter this exclusion. They promoted the production of informational materials, comparing updated knowledge about the epidemiological situation in various regions of the country, and producing reliable data on deaths, infections, and recoveries, independent of the federal sphere. This type of activism demonstrates the vitality of society in resisting what was perceived as the disorganization of the participatory mechanisms of health policies established post-1988 and was crucial in saving lives amidst a context of precariousness.

¹ David J. Rothkopf used the term infodemic to describe the volume of misinformation caused by the SARS epidemic in Asia, which, according to the author, was more dangerous than the virus itself.

We can identify at least three significant instances of Brazilian civil society's proactive response to the government's management of the health crisis in the country: 1) the campaign "**Omission Is Not Public Policy**," which brought together various civil entities²; 2) the formation of a consortium of commercial media outlets to provide the public with updated and reliable information about the pandemic, by verifying dubious or outdated statistics often provided by the government (Ferreira, Christofoletti, 2024); and 3) the emergence of associations of victims and family members of victims of COVID-19 seeking state compensation. In the parliamentary sphere, criticism of President Bolsonaro's handling of the pandemic led to the establishment of the COVID-19 Parliamentary Inquiry Commission (CPI) in the Senate, which investigated the actions and omissions of the federal government in addressing the pandemic, seeking evidence of the responsibility of public authorities who contributed to the worsening of the health crisis³.

This dossier originated from a roundtable discussion (MR46) titled *Políticas de combate à pandemia da covid 19 no Brasil, democracia sanitária e direito à saúde*, held on October 21, 2021, during the 45th Annual Meeting of the National Association for Graduate Studies and Research in Social Sciences (ANPOCS)⁴. The aim of this collection of articles is to critically examine state responses to the COVID-19 pandemic, which began globally in March 2020, in terms of prevention, combat, and vaccination efforts, as well as the social consequences of the health crisis, including social stratification, social connections and interactions, the emotional conditions of frontline healthcare professionals, and the recognition of risk work by patients and society, as well as collective efforts to address the damage caused by the disease. We consider the relationship between the state and scientific knowledge production institutions, as well as records of popular epidemiology in our country.

The Brazilian government, as has been widely discussed, questioned the real severity of the situation and was hesitant to mobilize the previously established scientific and technological capabilities in Brazil, particularly within public research institutions. We can also highlight the issue of public funding structures for vaccine development and the underutilization of the country's institutionalized

² Amnesty International Brazil, Oxfam Brazil, Institute of Socioeconomic Studies (INESC), Brazilian Institute for Consumer Protection (IDEC), Criola, Brazilian Association of Collective Health (ABRASCO), Indigenous Missionary Council (CIMI), Terra de Direitos, Coordination of Indigenous Organizations of the Brazilian Amazon (COIAB), National Human Rights Movement, Observatory of Metropolises, OLODUM, South American Network for Environmental Migrations (RESAMA), Global Justice, CEDECA, Engajamundo, Institute of Black Women of Mato Grosso (Imune-MT), Brazilian Association of Doctors for Democracy (ABMMD), Voluntary Support Group, and Association of Victims and Families of Victims of Covid-19 (Avico Brasil). Available at: <https://abrasco.org.br/omissao-nao-e-politica-publica/>. Accessed on 22 GO. 2024.

³ BRAZIL. Legislative Activity. CPI da Pandemia. FEDERAL SENATE. Available at: <https://legis.senado.leg.br/comissoes/comissao?codcol=2441>. Accessed on: August 22, 2024.

⁴ 45th Annual Meeting of ANPOCS. Available at: <https://www.anpocs2021.sinteseeventos.com.br/site/capa>. Accessed on: August 22, 2024.

research framework by the federal government, not to mention the president's role in promoting gatherings and disseminating misinformation about the consequences of COVID-19, treatment therapies, and containment measures. Additionally, we can address the place of denialism regarding the severity of the pandemic and the disregard for scientific evidence and guidance in the federal government's public actions during the health crisis.

We would like to emphasize that the articles provide a critical overview of the COVID-19 pandemic in Brazil and focus on the intersections between pandemic response policies, sanitary democracy, and the right to health. The emphasis here is on the results of empirical research and theoretical work based on national and international experiences of living, coping, relating, working, producing knowledge, acting collectively, and feeling during pandemic times.

The dossier offers analyses of the social impacts of COVID-19 on populations and the functioning of social spheres, contributing to the understanding of the health crisis in a situated manner, considering its scientific, social, political, historical, and cultural implications.

One of the most striking scenes in our daily lives, imposed by the health crisis, particularly between 2020 and 2021, was the widespread use of surgical masks as a gesture of protecting oneself and others from the proliferation of the novel coronavirus. Like other countries, Brazilian states adopted social distancing and masks as a physical barrier to prevent the release of droplets into the air from coughing, sneezing, and conversational acts, which can inadvertently expel saliva. Lidiane Soares Rodrigues' article, using a comprehensive and non-prescriptive approach to mask usage, discusses this practice in São Paulo in 2020, shedding light on some of its dimensions (symbolic, sociological, and political). Initially, the author proposes a typical ideal characterization of the "pandemic way of life," emerging from the limits of adopting previously effective ordinary hygiene methods, which were challenged by the rapid spread of the virus. Thus, there is a need to incorporate other cleaning practices, such as using hand sanitizer, to comply with non-pharmacological and preventive measures against the spread and contamination by the "novel coronavirus." Lidiane points out the adjustments experienced by people in their "cognitive and bodily schemas," and particularly the new ways of controlling the "presentation of oneself" through the "face-head" – a part of the body subjected to a contradictory regime of virtual display and physical covering. In the second part, the tensions between the demands for self-presentation (in its symbolic dimension) and the mandatory use of masks – both sanitary (recommended by medical expertise) and political (imposed by the State and subject to penalties) – are highlighted. Finally, the text concludes with peculiar attitudes towards mask usage, such as "premature" voluntarism, resistance, negotiation, and stylization. Thus, from this framework, the routinization of the "pandemic way of life," particularly encouraged by the state

government at the time, aligned with international crisis management guidelines, is discussed.

Contrary to the World Health Organization's health guidelines, in their article on the "memetization" of Bolsonaroist discourse throughout the pandemic, authors Sayonara Leal, Fabiana Mejia, and Fábio Nobrega Jr. explore one of the most visible aspects of the pandemic experience in Brazil: the use of social media to spread misinformation, alternative treatments without scientific efficacy, and criticisms of opposition leaders. The use of memes proved to be a powerful tool in disseminating incorrect information and inciting hatred and confusion regarding measures taken by governments, especially state and municipal authorities that insisted on following technical guidelines in accordance with global consensus. This proliferation of memes and the transformation of the public sphere into an increasingly digital polis presents new dilemmas for democracy (sanitary) and the relationship we establish with expertise.

The effectiveness of transforming memes and social media into weapons in political disputes is increasingly a prominent aspect of public life. The way these new communicational dynamics develop also influences responses to crises and emergency situations, such as COVID-19 and other potential future pandemics. Understanding this effectiveness was also one of the goals of the article by Marko Monteiro and Gabriela Di Giulio: by exploring the successful Bolsonaroist communication amidst the emergency, the authors demonstrate how these forms of communication reached both frontline professionals, such as doctors and municipal managers, who widely prescribed medications not sanctioned by scientific expertise. This impacted medication sales and local COVID-19 response policies.

The article further argues, in theoretical terms, that the category of denialism does not fully capture or accurately describe how science and expertise were mobilized or demobilized by authorities and Bolsonaroism throughout the pandemic. By showing how inaction was a crucial strategy of Bolsonaroist authorities (as evidenced by the widely discussed lack of federal coordination of the SUS in the COVID-19 response), the article argues that expertise was not merely ignored or attacked but was mobilized by both sides in different ways to support and legitimize radically distinct responses to the disease. Understanding these aspects helps to more accurately describe the decision-making patterns that marked the pandemic, the ways in which the population responded to the highly effective Bolsonaroist communication, and how alternative expertises imposed themselves in many state spheres, resulting in what the authors term active inaction and governance by chaos.

A comparative perspective also helps to identify similarities and differences between different countries, particularly concerning apparent failures in responses. An exemplary case is the comparison between the United States and Brazil, both

countries governed during the pandemic by right-wing populist leaders who persistently attacked scientific consensus and subverted expertise in favor of alternative and unproven treatments. In their article on denialism in these two countries, authors José Miguel Rasia, Soraya Vargas Cortes, and Alexandre Ribeiro Martins analyze editorials from major newspapers to understand how the pandemic was discussed in politically conservative newspapers.

One significant finding by the authors was the denial of the emotional impact on people suffering from the immense losses caused by COVID-19: whether due to deaths, job losses, or the loss of minimal normalcy, COVID-19 caused considerable emotional distress for billions of people worldwide. The strategy of denying the severity of this pandemic, as seen in leaders like Trump and Bolsonaro, is particularly striking. The authors show how newspapers discussed fears and anxieties, such as loneliness and fear of death, and how these themes were present at specific moments during the pandemic. Like Monteiro and Di Giulio, the authors here highlight the absence of explicit action in politics: the lack of empathy, in these cases, was part of the political strategy adopted by these leaders, which remains a little-discussed topic in the COVID-19 literature.

Much has been said, and continues to be said, about alternative treatments suggested in Brazil and other countries to combat COVID-19. One of the most well-known and publicized was hydroxychloroquine, a drug with a long history and widely used in Brazil for treating known diseases, such as malaria and autoimmune disorders. The article by Luiz Villarinho Pereira Mendes, Claudia Garcia Serpa Osorio-de-Castro, Marilena Correa, and Ilana Lowy explores the history of this drug, seeking to understand a paradox that still fascinates: how was it possible for leaders like Bolsonaro and others to so broadly and insistently support this treatment? What does this reveal about politics and the relationship with science in the country? The article provides a detailed exploration of the rise of this drug and how it was increasingly incorporated as a treatment. It is interesting to consider the technical-scientific information circuits between countries, such as Brazil and France, given Didier Raoult's central role in the hydroxychloroquine case. These circuits carry not only scientific information and data but also alternative views of expertise that significantly impact political and public health options.

Few topics have been more silenced and/or ignored by politics and subsequent literature on COVID-19 than intersectional issues involving race, gender, and class, and the impact of these disparities on the progression and consequences of the pandemic. Numerous studies objectively show that the losses caused by COVID-19 disproportionately affected Black, Indigenous, peripheral, and other vulnerable groups. Despite this, little to nothing was discussed about these issues during the pandemic, and even less has been addressed in studies aimed at understanding its impacts. In this regard, the article by Flora Rodrigues Gonçalves, Polyana Aparecida

Valente, and Bráulio Silva Chaves helps to fill this gap by analyzing how quilombola territories in Minas Gerais responded to the pandemic.

The article emerges from the engagement between academic institutions and quilombola female leadership, thus operating at the intersection of popular education, knowledge production, and outreach. The widely criticized void in federal government leadership brutally impacted these women and quilombola populations, creating a necropolitics of “letting die” that went far beyond the herd immunity strategies present in the overall Brazilian response. By giving voice to these women and their struggles, the authors’ work highlights both the potential for death inherent in a structurally racist and exclusionary policy and also helps to identify forms of resistance that organize in contexts of extreme vulnerability, bringing hope for change, including through alliances with academics engaged with these subjects and their realities.

In a more essayistic format, André Le Breton’s text provides an anthropological analysis of how the health crisis illustrates the close interdependence between our societies and, above all, the impossibility of closing borders to health risks, such as the novel coronavirus. The author argues that the pandemic imposes biopolitics due to issues that transcend national boundaries. In this sense, social immunization through masks, physical distancing, and limited contact become internationalized, reminding each of us of our fragility as living beings and our susceptibility to existential precarity. Le Breton posits that the spread of the coronavirus induces a “democratization of danger” within the frenetic pace of globalization.

From the perspective of emotions, Adrian Scribano’s article approaches hope as an epistemic and subjective tool capable of forging a new notion of personhood. The author argues that the concept of personhood within the context of COVID-19 paves the way for a “revolutionary dispositionality” to improve collective life and health. This approach to the global public health issue of the novel coronavirus emphasizes the social, political, and affective sequelae of the pandemic, as the author suggests the possibility of converting the negative impacts of the health crisis (grief, fear, uncertainties) into promising effects for addressing future crises that threaten planetary well-being. From the plurality of situations in the field of public health, Scribano posits the convergence of hope with revolutionary practice. The text presents hope both as an emotion and as a “civic virtue,” leading to radical changes in the constitution of individuals, communities, and society, operating in the relationship between humans and the planet and all living beings inhabiting it. It is a political pedagogy based on emotions that views critical moments as opportunities to observe hope as a cognitive and reflective trigger capable of overcoming the imminence of death during times of pandemic.

Finally, the contribution of Karina Batthyány and Valentina Perrotta focuses on the Uruguayan response to the COVID-19 pandemic, demonstrating that despite

Uruguay being the first country in the Latin American region to approve a law in 2015 recognizing the right to care and establishing the National Integrated Care System (SNIC), the government's management of the health crisis was criticized. According to the authors, the five years of implementing a care system that aimed to redistribute caregiving responsibilities, with the state assuming a greater role in its provision, did not support the Uruguayan government effectively combating the virus in 2020.

Karina and Valentina highlight that, among Latin American and Caribbean countries, Uruguay was the least proactive in adopting measures to protect the right to care during the pandemic, precisely when this demand increased substantially due to the isolation of individuals in domestic settings, the closure of educational institutions, and the added "romanticization of staying and working from home." The pandemic coincided with the inauguration of a government with a political orientation different from that which had promoted and established the SNIC. The elected right-wing coalition prioritized reducing the budget deficit as a central goal of its government program. The article discusses what happened to the right to care during the pandemic in the country, emphasizing that the residual conception of the state's role and an approach to care associated with familial and private responsibility runs counter to the law that established a collective health care system five years earlier. This resulted in a slowdown in the expansion of health service coverage and the suspension of some services, a reduction in social participation, significant conceptual setbacks concerning the consensus reached on the notion of care, a contraction of democracy in health, and an increase in social and gender inequalities in the country.

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