Solidarity, citizenship and social justice: perceptions of social actors about public responses to COVID-19

Abstract  This qualitative study aimed to analyze the social actors' perceptions of public responses during the COVID-19 pandemic. We conducted semi-structured interviews with eleven civil society representatives and social movement leaders. We also performed triangulation based on the systematization of opinion papers authored by humanitarian organizations and civil society leaders and published in large-circulation newspapers. Our analysis was inspired by the ethical principles of social justice, solidarity, and citizenship. Two main themes emerged from the thematic analysis: 1) disproportionately affected populations remain invisible to care and protection; 2) there is an intentional project to annihilate "undesirable" populations. Community movements must be incorporated as an essential part of the responses to provide care and protection and mitigate the effects during health emergencies. Care, solidarity, and social participation are central to building health protection responses within the framework of social justice. The responses to transforming the future in the aftermath of the pandemic will occur through the initiatives of civil society and community leaders within the territories.

Key words COVID-19, Social justice, Social participation, Public health, Care
Introduction

The effects of the SARS-CoV-2 pandemic in Brazil can already be considered of tragic proportions. Paradoxically, the country has one of the most advanced health care legislations. Health has been a fundamental right and an obligation of the State since 1988 in Brazil — and Law 8.080 of 1990 materialized the Unified Health System (SUS), realizing the conditions to ensure free and universal health for all. Brazil was a world model for the treatment of HIV/AIDS and had an enviable vaccine capacity and coverage with vaccination campaigns nationwide, even for the countries of the global north that led the ranking of vaccination in this pandemic. Currently, the world turns its attention to our country, not because of health care advances but because of the tragedy of being one of the main epicenters in the number of COVID-19 deaths. We have been tragically turned into an open-air laboratory for mutating more contagious and deadly strains due to the high contamination rates.

The Brazilian situation causes concern not only from a national perspective, as global humanitarian organizations and the international scientific community also discuss the Brazilian backdrop. The organization Doctors without Borders released a note in April 2021 in which it points out that “the failure to respond to COVID-19 leads Brazil to humanitarian catastrophe”. In an editorial, The Lancet discussed the “federal vacuum in political actions” — especially mobilized by the rhetorical question of then-President Jair Bolsonaro, who, when asked about the thousands of dead, replied: “So what?”. The newspaper also listed a structural challenge in which, despite the current federal government, the country was already facing historical imbalance and social inequalities. The editorial pointed out that during the pandemic and without responses from local authorities, the Brazilian challenge will be to protect people living under historical vulnerability layers — such as the thousands of Brazilians living in slums, the other thousands of informal workers, and indigenous people.

We should consider the vast literature that discusses preparedness and response to a public health emergency. Epidemics and other health emergencies highlight pre-existing vulnerabilities. Then, it is essential to revive the debate on ethical values related to equity, dignity, solidarity, justice, and the common good. These values will undoubtedly mitigate the impacts of a public health emergency on the population, especially groups already historically unprotected in a context different from countries with more significant economic development. In this sense, ethical reflection becomes central in facing the pandemic when we observe false dilemmas in the narrative of public managers or authorities that put the economic agenda and the preservation of lives in conflict, making them excluding.

Authors have discussed the importance of learning from collective experiences about responses to the care of populations during health emergencies. In a situation of scarce resources, it is still an ethical obligation to plan how resources will be allocated, considering historical inequalities in access to health and factors related to structural racism, poverty, gender inequality, and discrimination, among other factors that can make specific populations more vulnerable to morbidity and mortality due to the pandemic. Authors also point out how the specialized literature has naturalized gender, race, and class differences when analyzing risk factors for illness by COVID-19 or its severe consequences.

It seems central to us to consider intersectional lenses and the principles of justice as an ethical and secular imperative in the debate about planning responses and distributing scarce resources during a health emergency such as the current pandemic. Equity in the distribution of limited resources, prioritization of historically marginalized populations, continuous provision of primary health care and social assistance services, and respect for human rights are some essential elements for a practice grounded on the principles of social justice for responses to health emergencies.

The COVID-19 pandemic has mirrored the historical inequality of Brazilian society. Thus, it seems essential to us to reflect on the ethical challenges in building responses and policies in a public health emergency, especially considering that we live in a country with profound inequalities in access to health and distribution of social and economic resources. Evidence shows that the populations disproportionately affected are already experiencing the historical consequences of illness due to social determinants related to the unequal distribution of resources, structural racism, and geographic inequalities.

It is not uncommon to see the articulation and organization of groups and community leaders, social movements, and civil society to guarantee protection and solidarity networks when there are no significant responses from
state authorities for people’s care and protection. Democratic solutions based on cooperation and solidarity are implemented through community and citizen mobilization initiatives. Recognizing citizenship in the existence of the other is fundamental for recognizing a dignified life, the assurance of rights, and the sharing of a political community. From this perspective, this paper aims to present an analysis of civil society representatives’ perceptions of public authorities’ responses to the care and protection of specific population groups during the COVID-19 pandemic. Our analysis was inspired by the ethical principles of social justice, solidarity, and citizenship.

Methodological path

This research is nested in the study “Ethics and bioethics implications in response to the public health emergency: an analysis of coping with the COVID-19 pandemic in Brazil” (our English free translation). Our reflection is based on the analysis of data collected in one of the stages of the study, which consisted of conducting interviews with key stakeholders representing organized civil society. This is a qualitative stage and therefore focuses “on the meaning of real-life events, not just on the occurrence of events” (emphasis by the author). We aimed to analyze the perceptions of social actors related to the distribution of resources during the COVID-19 pandemic and their perceptions of the responses of public authorities to the care and protection of populations.

We conducted semi-structured interviews with eleven civil society representatives appointed by leaders of social movements. Men and women aged from 35 to 68 years were among the representatives interviewed. They primarily defend rights related to women and feminism; the Black population; indigenous people; the riverside population; residents’ association; the right to education; the LGBTQIA+ population; trade union and workers’ movement; movement of people with disabilities. The interviews were held from January to March 2021.

We performed data triangulation to achieve a composition with a greater scope and ensure the analysis of a diversity of voices. We also used the survey and systematization of opinion papers authored by representatives of social movements, humanitarian organizations, and civil society leaders published in widely circulated newspapers on digital platforms about perceptions of injustice related to the Brazilian State’s responses to the protection and care of populations during the pandemic. One hundred fifteen pieces were collected in six press vehicles, published from April 2020 to May 2021. The survey was conducted from May to June 2021.

Data were analyzed using the thematic analysis technique. After transcribing the interviews, the analysis was carried out by coding the excerpts line-by-line. Thus, data coding followed two procedures: guided analysis asking questions about the data and, at the same time, comparing them. After the coding process, we classified the coded excerpts for the composition of the analytical themes. Two main themes emerged regarding the perception of public authorities’ distribution of resources and responses during the pandemic in our analysis, which we will discuss in this paper: 1. Disproportionately affected populations remain invisible to care and protection; 2. There is an intentional project to annihilate “undesirable” populations.

The Research Ethics Committee of the National School of Public Health Sérgio Arouca – ENSP/Fiocruz approved the research under CAAE 36571120.0.0000.5240.

Results and discussion

Disproportionately affected populations remain invisible to care and protection

The specialized literature has already widely discussed that public health emergencies disproportionately affect historically unprotected populations. In this sense, the themes of justice and equity seem fundamental when discussing the distribution of resources for health care and actions during pandemics and epidemics. Here, we understand health as a complex and multifaceted event that incorporates aspects related to moral values, encompassing emotional, physical, spiritual, social, and intellectual dimensions. Therefore, it does not seem possible to hold a debate on public health separated from the issue of social justice.

Participants in this research described their views on responses by public authorities in the pandemic in a direct connection between public health and social justice, as presented by one of the participants below:

These people [in conditions of violence and vulnerability] were, are, and will always be the biggest victims of COVID-19. Because they are the biggest
victims of this country and society as unequal as ours (Participant A).

The statement transcribed above may seem obvious to social movement representatives, scholars on the topic, and advocates of SUS principles and guidelines. That is, despite a pandemic launching unexpected situations to biopolitics, previous processes of precarization make some lives even more fragile to the effects of the virus. Some statements by civil society representatives also provide evidence of how responses to the pandemic in Brazil ignore standards of equity in the planning of actions, supplies, and services for a fair distribution of resources for health care. As reported by one participant:

If someone doesn’t have drinking water, imagine what else they don’t have? Inequalities in this country are rising. We have a sort of scarcities, and all of them together produce our tragedy (Participant B).

In the last five years, we have also faced another public health emergency of humanitarian proportions: the Zika virus crisis, which has mainly affected women of reproductive age and was understood as a global threat but quickly forgotten despite its perpetuating legacy. A common point between the two emergencies is that both mirror Brazilian inequality – especially from the perspective of class, race, gender, and disability. Life protection policies have historically neglected the populations disproportionately affected in both health crises. We could say that the tragedy pointed out by the participant was built through decades or centuries of invisibility of some “killable” bodies, in contrast to other bodies protected by politics of life.

In this sense, the participants point out that there is no adequate response plan for the care and protection of populations in this pandemic context. In other words, there is no plan for the present and future actions to ensure that layers of vulnerability are not exacerbated, nor to prevent the heightened state of precarity. The body’s ontological precariousness should impose a moral obligation on us to care for life to ensure conditions to protect it. However, life’s value is produced not by its existence as itself but through specific power mechanisms – in which some lives are apprehended as worthy of recognition for protection and flourishing, while others are ignored.

The debate on the scarcity of resources affects structural problems, especially when considering aspects related to social determinants of health and intersectionalities such as racism, class, or gender inequality. When inequalities are ignored, responses can only escalate the harmful effects that disproportionately impact populations historically discriminated against, perpetuating those inequalities. Participants point out that they deem homogenized responses unfair, disregarding previous settings of inequalities:

I think injustice is imagining that everyone is the same, right? That the answer is the same for everyone (Participant C).

One of the participants pointed out the allegory “we are in the same boat” as the result of trivialized inequality. Solidarity appears as a fundamental value but is hardly recognized among those who live in privileged layers.

That first narrative ‘we’re all in the same boat’ shows the scarcity of empathy and solidarity. It shows a society that is not bothered by deaths, hunger, or disadvantages (Participant D).

Civil society representatives point out that the thousands of preventable deaths in the pandemic are not seen as a tragedy; on the contrary, they become naturalized. In this sense, the hegemonic norms that define the marks of recognition and valorization of lives designate the recognition of deaths differently. Suppose everyone is “in the same boat”. In that case, the disproportionate concentration of deaths among black populations and living in marginalized geographic regions are not considered since, for example, in the case of maternal mortality due to COVID-19, in which deaths of black women are twice as high as white women.

The discourse that we are all “in the same boat” therefore ignores these inequalities and, at the limit, devalues the loss of thousands of lives disproportionately impacted by the pandemic.

We defend the importance of the debate on the ethical principle of solidarity. However, if we do not bring it to the fore of the analysis through intersectional lenses, solidarity runs a severe risk of being hollowed out. We consider intersectionality an ethical perspective for analyzing power regimes that oppress, exclude, and violate specific populations to perpetuate the privileges of other populations that are already historically and socially included as deserving of care and protection. In this sense, we can understand solidarity as a set of experiences based on the ideals and practices of democratic reciprocity, but also from the perspective of a political commitment to fight against oppression, sharing interests and beliefs in respect of diversity.
Thus, the current Brazilian political situation for composing the responses of public authorities that are considered solidary is a challenge. Participants pointed out that there was no perception of solidarity between hegemonic groups and those historically and socially oppressed, nor institutional solidarity in public policies for the care and protection of the most affected ones. At the same time, there is a feeling of solidarity between different representatives of civil society because, despite the diverse agendas, there is a common understanding that the answers exclude and traverse the groups. In other words, there is a shared perception that the responses of public authorities to face the pandemic are exclusionary and exacerbate inequality and vulnerability of lives, especially concerning violence and the scarce resources that impose themselves as a historical and structural issue.

Next, we will discuss a second interpretative path, which is also linked to absence — that there is an intentional omission of care and protection.

There is an intentional project to annihilate “undesirable” populations

Unintentional consequences refer to unforeseen effects — which, therefore, could not be anticipated by responses to protect and care for populations\(^3\). Let us consider that our country’s structural inequalities are still widely debated among social actors and experts. We can understand that, regarding the responses of Brazilian public authorities to the COVID-19 pandemic, there is intentionality placed before this tragic setting of preventable deaths. The report “Rights in the Pandemic – Mapping and Analysis of Legal Standards for the Response to COVID-19 in Brazil” (our English free translation), which systematized and analyzed 3,049 state and federal standards in response to the new coronavirus pandemic, concluded that public authorities implemented a deliberate strategy of spreading the virus\(^3\).

Civil society representatives were also concerned about what they call an intentional project of suppressions and silencing, also described as genocide:

“The pandemic ends up being used as an instrument to implement this policy; a genocide declared against us, you know?” (Participant D).

In an interview with El País in July 2020, Deisy Ventura\(^3\) highlights signs of an ongoing genocide policy in Brazil during the pandemic. Ventura defines genocide as a crime against humanity, in which extermination actions and “deliberate subjection to living conditions that can destroy part of the population”\(^3\). Cida Bento\(^3\), in turn, describes the responses as policies of the “death lords”, in which these stakeholders exercise bureaucratic and institutional power that deliberate on policies and allocation of resources – for Bento, they would be the lords “with a pen in their hand: the decision-makers”. We can understand the death lords as those who can exercise power and drive extermination policies, as described by this civil society representative:

“The government’s measures are proving, step by step, its intentionality. When we say genocidal, it’s not rhetoric. It’s a fact. There is an intention to eliminate it, leave it in oblivion, and leave it to one’s fate. Thus, this is indeed a genocidal policy” (Participant E).

Michel Foucault\(^3\) brings the concept of biopolitics to discuss the power technologies that target populations’ lives. Biopower works at its maximum level during health emergencies: tactics to control the bodies of populations are designed in the name of security and defense of society against a common enemy, which in this case is the new Coronavirus. However, not all populations are cared for and protected. Foucault\(^3\) points out that racism in biopolitics would be what would allow the State to exercise a power over life through the death, even if its justification is, in theory, the preservation of the life itself. If the murderous role of the State operates through racism\(^3\), intervention to make people live is not for everyone but only for those whose lives are worthy of value.

Achille Mbembe\(^2\) proposes the notion of necropolitics. He says biopolitics is insufficient for contemporary reconfigurations. Necropolitics would be understood as a political power toward death to control people\(^7\). Civil society representatives do not bring theoretical concepts, but describe the power tactics that exposure their lives to the deadly form of power through the testimonies of their experiences.

“We see a discourse that life is worth it, but whose life is guaranteed rights? Is it indigenous life? Is it the quilombola life? Is it the marginalized life? What is the life that people prioritize?” (Participant D).

The questions listed above are not mere rhetoric but genuine questions about the norms of recognition for protecting lives during a health emergency. The policies of foster life or disallow it to the point of letting die are pushed to the lim-
occupancy between 82 and 97%. All the evidence indicates that people’s socioeconomic, health, and well-being impacts will be felt for a long time.

It should be noted that the effects are even more perverse for populations historically discriminated against and victims of structural racism. In the absence of the State’s responses, organized civil society has articulated itself to ensure equity in the responses and qualified data for constructing public policies. In 2020, the Articulation of Brazilian Indigenous Peoples (APIB) filed a lawsuit with the Brazilian Supreme Court (STF) to protect indigenous peoples during the pandemic. In the same year, the Black Coalition for Rights filed a request with the Ministry of Health for the stratification of the ethnicity/skin color issue to disseminate epidemiological data on infected and dead by COVID-19.

Our existence is being put in check. We are fighting for the basics: to exist, to be able to exist (Participant D).

The justification for the importance of community participation is regarding the struggle for the right to health under the framework of social justice and linked to the struggle for survival. From this perspective, we can consider that the participants’ statements – even from different historically oppressed identities and racial groups – shared the transversality of not being included in the responses formulated by the Brazilian State. As a result, the State responses have supporting the reproduction of privileges and which, consequently, aggravates the scarcity of resources. A shared perspective between the different civil society representatives provides us with the connection of the collective image that presents this shortage and almost non-existent and excluding responses, as they are disconnected from people’s needs.

Final considerations: community and citizen participation in facing the health emergency

The responses to this health emergency have considered populations in general terms. However, we should consider that structural inequalities impose layers of privileges for specific bodies within their specificities and needs. In this sense, there are no populations in an abstract perspective: when we talk about people, we need to consider that we all inhabit a body with gender, color, and class, some of us with disabilities. We also inhabit different geographies. In other words, the abstract rules for the prevention, response, and mitigation of the effects of the pandemic ignore inequalities and, for this reason, expand the layers of vulnerability of people already historically discriminated against and oppressed – putting specific populations at greater risk of illness, poverty, and death.

If responses during health emergencies incorporate the reality of inequalities, we should recognize the importance of community movements as a central part of care and protection networks. The consequences of the pandemic will be suffered in long-term. Thus, community actions must build strategies for the protection of people today but also their care in the post-pan-
emic future. Moreover, the transformation of the post-pandemic future will come from the responses offered by health workers on the frontline of care and through civil society initiatives and community leaders within the territories.

Care, solidarity, and citizen participation seem to be the keys to building responses for health protection within the framework of social justice. Care relates to values but also practices. As further evidenced by the pandemic, our survival depends on care relationships with others, as there is no social justice without care. Thus, no one can be left out. We need to listen to women and other discriminated and racially oppressed groups and include them at the core of the responses.

Collaborations

All authors participated in all stages of the elaboration of the paper. L Brito wrote the first version that was successively revised and modified by the other authors, RL Santos and S Rego until we reached the current content and format.

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