Organised groups, social activism and narratives of the pandemic in vulnerable territories in the city of Rio de Janeiro, Brazil

Abstract The COVID-19 pandemic has reached alarming levels in Brazil. In Rio de Janeiro city, it arrived in a scenario in which Primary Health Care (PHC) was being dismantled in the midst of a political crisis, which had major impact on the most vulnerable territories. This study examined how favelas and PHC teams organised community-based action and occupy the vacuum left by the lack of public policies. The results form part of the multi-centre qualitative study “Strategies for approaching subjective and social aspects of Primary Care in the pandemic context”, using public guidance documents and 36 in-depth interviews of PHC workers and users, which were categorised into interpretive grids. Co-management initiatives by PHC workers and users were found to have arisen out of organised groups and social activism, to face the pandemic, independently of regulations from the Municipal Health Department and other government bodies. PHC figured as the only public facility in highly vulnerable territories, where armed violence was ongoing even during the pandemic.

Key words COVID-19, Political activism, Primary Health Care, Social vulnerability, Qualitative research
Introduction

The COVID-19 pandemic found favourable conditions to spread in Brazil. The federal government’s position, exempting itself from responsibility for health care, distorting the facts, denying scientific evidence and disregarding World Health Organisation guidelines, allied to the social and public health conditions of much of Brazil’s population, soon placed the country at the global epicentre of the pandemic1. Favoured by federal necropolitics2 and the public’s enormous difficulty in adopting protective measures and complying with health guidelines published by state and municipal governments, the pandemic soon reached territories where the most vulnerable populations live, causing irreparable losses.

The pandemic’s arrival in Rio de Janeiro was marked by one emblematic event: the first COVID-19-related death in the state was that of a housemaid, who contracted the disease from her employer, who had just arrived from Italy. Resident in the town of Miguel Pereira, in a hilly area of the state, the maid slept during the week in the house where she worked, in the district where real estate prices are the highest in Brazil, returning to her hometown only at weekends. With time, the realisation dawned that this pandemic that killed and left people defenceless, heightened already existing inequalities3.

Of the public policies that these populations could rely on, the Unified Health System (Sistema Único de Saúde, SUS) stands out. The importance of a robust SUS, with strong Primary Health Care (PHC) organically connected with the population and their way of life, was demonstrated more than ever in response to COVID-19. PHC, its bonds with the community and knowledge of the territory were salient strategic features in health surveillance, communication, prevention of contamination, identification and support for groups of vulnerable people4-7.

On the other hand, the State was largely absent from the most vulnerable territories, which fostered the emergence of organised groups and social activism8 to meet the population’s basic needs in a socioeconomic crisis aggravated by the COVID-19 pandemic. That movement could be seen in some favelas in Rio de Janeiro city6,9.

This article examines how local communities and PHC workers in vulnerable territories in Rio de Janeiro city organised and integrated to take community-based action and occupy spaces left by a lack of public policies.

Methodology

This article forms part of “Strategies for approaching the subjective and social aspects of PHC in the pandemic context”, a research project conducted in three municipalities in Brazil’s southeast region. In Rio de Janeiro, researchers went into the field between July and December 2021 in four territories: Jacarezinho, Rocinha, Catumbi and Manguinhos. The choice of these territories obeyed two criteria: social vulnerability (resident population mostly of African descent, family incomes of less than three minimum wages and precarious housing and basic sanitation conditions and other basic services were accessed primarily in the form of public services). The second was at the recommendation and interest of municipal government, which assessed these locations as offering conditions for this study.

When the empirical phase of the study began, the epidemiological situation in the municipality was not favourable to entering these territories. Thus, the priority was for all researchers be vaccinated against COVID-19 and for health control measures to be taken.

The subjects were chosen on the understanding that, as actors, health workers and users are key to a proper understanding of the study objectives, added to which it was believed that there would be different experiences and perceptions with regard to the same object. Accordingly, parity was prioritised when inviting these two groups.

The criteria for inclusion of users in the study were: being 18 years old or more, living in a territory assigned to the PHC facility, who displayed substantial social and subjective features, such as constant and recurrent use of the service or difficulty in connecting with it, psychological distress with or without defined diagnosis, difficulty in carrying out self-care and intense use of medication. Priority was given to users who met at least three of the following criteria: women heads of families, community activists, residents in situations of social vulnerability related to work, income or precarious family and social ties, victims of violence, people with difficulty accessing health, education, social assistance and other services, members of marginalised populations, such as black people, people with disabilities, LGBTQIAP+, thus forming the research participant profile. The exclusion criterion was not being registered with the PHC facility. The inclusion criteria for health workers was being on the PHC staff and the exclusion criteria was having worked less than one year at the unit.
The first interviews were held at the indication of the PHC unit managers, as key informants, and using the snowball method. Subjects in both groups who confirmed their interest through the consent form were interviewed in person and at a location of the interviewee’s choosing, such as churches and squares, with most taking place at the PHC unit itself.

The criteria for completing data collection, in-depth interviews was the commitment to the research objectives, as well as the issues contained in a guide-map designed to function as a script for the interviews. The second group of criteria was the researcher’s assessment as to repetition of points, non-verbal communication and, relying on the sensitivity of each participant (interviewer and interviewee), the meeting’s touching on sensitive points that prejudiced the interview’s continuing. After each interview, interviewees were asked to evaluate the content of the interview, to establish whether or not they were interested in continuing at another time. The group of researchers then began a process of validating the interviews, to establish the interviews, the health workers identified the importance of the publications, although there were still gaps in institutional support in this critical period.

Analysis of these documents produced between March 2020 and April 2021 found that they were more informative than formative. In the interviews, the health workers identified the importance of the publications, although there were still gaps in institutional support in this critical period.

The documents offered guidelines for the facilities’ work process in response to the pandemic on topics such as oral health, rehabilitation, “Health Academy”, tuberculosis, smoking, drug care, and health of older adults, women and children. These were produced centrally, with little participation by the PHC units and, as a result, these guidelines were little absorbed into routine, while the health workers’ anguish at the uncertainties surrounding the need to adjust practices at PHC remained. Analysis of the repercussion of these documents provided a better understanding of the technical and policy context of PHC at that time.

The study was approved by the research ethics committee of the institution responsible for the study (CAAE 40699120.2.0000.5404) and by the respective Rio de Janeiro municipal department.
Primary Health Care in Rio de Janeiro

Historically, the local health care network features a hospital-centred model of care, including a large number of federal hospitals, which has not resulted in satisfactory health coverage rates or care quality for the population of Rio de Janeiro.

As a way of improving that situation, from 2009 onwards, coverage by the Family Health Strategy began to expand in the municipality, based on the model of management by Social Health Organisation. Another strategy used by the municipal health department was its commitment to implement medical residency programmes as a means of providing and retaining professionals in these units, and to install Family Clinics in vulnerable areas of the city, with a qualified ambience standard.

In 2017 the incoming municipal administration took advantage of the new National Primary Care Policy and began to dismantle PHC in the municipality: health teams and workers were cut back, working conditions became increasingly precarious and other setbacks were seen during the government at the time.

From 2021 onwards, the political scenario in the city changed again, raising great expectations among health workers and users for a resumption of investment in PHC, as well as in meeting important challenges posed by the pandemic.

Rio de Janeiro and its vulnerable territories, the research field

The municipality of Rio de Janeiro is known for its natural riches, but also for its disorderly urbanisation as regards unequal housing conditions and access to basic services. The four favelas that make up the study setting are in different areas of the municipality, as shown in Figure 1.

Results and discussion

Increasing social vulnerability, the response from PHC workers and organised groups

Most respondents mentioned increased unemployment and vulnerability impacting the lives of many families in the four territories. In addition to the thousands of deaths from the pandemic, many people fell into extreme poverty because of impossibility of carrying out the activities required to earn a livelihood. Most of the population attending the FCs lived in areas of major health and social vulnerability and suffered the direct and indirect effects of the pandemic, which caused the deaths of mostly black and poor people. The study also found that many PHC users had precarious or informal work, paid by the day, doing odd jobs, were bricklayers, street sellers and self-employed, with no social protection network, as can be seen from the following report:

My son lost his job, my daughter-in-law lost hers, I have a niece who also lost her job, as she took care of my sister, who died. So, every month, I help them out financially.

One of the users interviewed, whose daughter takes part in solidarity soup distribution in Rio city centre, reports a substantial increase in the number of people living on the streets and going hungry. The same was said in the words of one of the health workers:

There are a lot more homeless people. That’s dreadful, what we call hunger migration: people go where there will be more clothes or food donations... it got to where there were more than two hundred people coming together in search of food donations.

Also mentioned was users’ difficulty in complying with health guidelines on isolation, because they could not stop working: people wanted to stop and could not, because they were self-employed or informal workers.

Others were threatened with losing their jobs if they missed work, even if they were diagnosed with COVID-19 and had doctor’s certificate.

Another user’s statement pointed out that:

The informality meant that in June 2020 everything was open and people weren’t wearing masks, because people make their living here from the things they produce and the work they do; the favela feeds itself. Here there are shops, markets where you can buy on tick and pay at the end of the month. There’s no emergency aid, so that these people could stay indoors, so they go out to work because it’s urgent, they’re hungry, they have bills to pay.

In addition to the difficulties inherent to the disease itself, the economic crisis was worsening, making food more expensive, significantly increasing hunger, and adversely affecting families’ purchasing power and vulnerability:

When I go to the supermarket, I don’t like to go with my children, because they put products in the cart and when the time comes to pay, I have to choose, because there’s no money to spare.

Another user believed that:
Hunger will be the pandemic’s main legacy in Jacarezinho: people were already very poor, the 4th worst HDI in Rio de Janeiro... You already had a highly vulnerable favela from poverty, disease, public security, and now we have a more impoverished favela, with people who’ve lost their jobs because of the pandemic or not being able to go out to work because of the violence.

That panorama posed a need for the FCs to work with local assistance institutions. The scenario of increasing vulnerability led many users to seek guidance on social programmes, such as the Continuous Provision Benefit, the Family Allowance and others, such as Emergency Aid, set up during the pandemic. Elderly people not covered by social security sought guidance on the Continuous Provision Benefit, while other situations, in cases with no family ties or support network, required collaboration with social assistance services.

What one user said in this regard is quite emblematic. This mother of seven children moved from the Baixada Fluminense lowlands to the capital in search of opportunities in the expectation that, in a favela, she would not have to pay water or electricity bills. She said that the pandemic put her through extreme situations she had never experienced:

We have gone days without eating and sometimes I had to send my children to their parents or grandparents so that they would not go without food.

She told how FC staff provided basic food baskets and health care, as well as support in registering for social benefits. In the support she obtained, she saw how the FC was proactive in identifying users’ different needs and not limiting itself only to health concerns. One health worker reported how hunger had direct impact on her work process:

That difficulty existed before, but I think it was kept quieter. But now, they’re more open about the lack of money to buy food, medicine or to go for some test outside the clinic.

Social vulnerability also had significant impact on the implementation and permanence of health protection measures. Often, for example, it was impossible to comply with social isolation and mask use.

Last year there was no vaccine and [homeless people] had to stick together to survive in the cold. There was no other way.
Increasing family violence, directed especially against women, was observed in three facilities studied. We know that this kind of violence is yet another of the vulnerabilities that did not emerge with the pandemic, but were aggravated by social isolation measures\textsuperscript{19}. One interviewee reported that, after a survey by the Instituto de Segurança Pública in Rio de Janeiro, which mapped the days and times with highest incidence of violence\textsuperscript{20}, he began sharing alert messages on social networks around the times identified in the study:

I was approached by residents, who asked for help to stop the cycle of violence they were caught in.

Armed violence was another recurring theme from respondents. Jacarezinho, one of the most violent areas in the city, proved no different during the pandemic: in May 2021 there was a massacre with approximately 28 dead\textsuperscript{21}. Importantly, the killing occurred despite the restriction on police operations in Rio de Janeiro’s communities during the pandemic, save exceptional cases, voted in August 2020 by the Federal Supreme Court\textsuperscript{22}.

Even in this scenario of extreme armed violence, some users said they felt good about living there, although recognising the upheaval caused by the violence. Overall, the four territories are spaces where armed conflict is ongoing. Nonetheless, older people reported enjoying residing in the community and life there:

As regards the violence, it had calmed down. There was only that killing a few months ago with 28 dead. Other than that, it has been quiet, because there were no police. No police, no confrontation. In that massacre, the police went all out. But I think it actually took a long time for them to scour the neighbourhood. As you enter the community, there are a load of iron barricades. If someone dies at home, you have to put them in a wheelbarrow and take them down to the road, because ambulances can’t get in. But no-one bothers you here. You can come and go as you please. Their business is to sell that stuff of theirs over there and we stay over here.

Living with violence is also part of the day-to-day of whoever works in these territories, and people perceive it in different ways:

Some of the staff have been here a long time; others couldn’t take the pressure. There are times when you have to stop care in the middle and hide under the table to escape the bullets. I tell them we don’t accept bad things, but we do adapt.

Other personnel pointed to the adverse effects of episodes of violence on their health:

I live in Botafogo and it’s really hard having to cope with that contrast every day: leaving Jacarezinho and going to the south zone is a constant emotional effort... Having to deal with this problem and with the effect of the violence on individuals, that’s really hard.

Organised groups and social activism

Notable in the accounts was that organised groups were an active presence, especially in Catumbi, Rocinha and Jacarezinho, and constituted an important strategy of social activism during the pandemic in response to the lack of any hard-hitting protective action by the public authorities in these places. Note that, in both its locus and political trajectory, this mobilisation was built up with an eye to local diversity, community organisation and available resources, demonstrating these groups’ ability to mobilise support, form partnerships and build networks\textsuperscript{1,3,9,19}. Interviewees described the main objectives of these collectives as being to protect and support the most vulnerable, address the impacts of the pandemic, organise the collection and distribution of basic food baskets and supplies, such as masks and alcohol:

A lot of people arriving on the street for the first time. Emergency aid was given, but people who really needed it had almost no access to it, because you needed at least an identity document and the office that issues the documentation was closed.

The FCs were strongholds of community support in coping with the pandemic in the territories. The staff supported the groups in providing basic food baskets and health care, as well as supporting registration for social benefits. One initiative by these organised groups was to register the most vulnerable residents in the Catumbi favelas, where bedridden people and those with severe health problems were mapped at the request of the CHWs. In addition to identifying these patients, their help included delivering medicines and basic food baskets, as well as procedures that did not require the presence of the FC user:

We did the monitoring with support and guidance from the FC via WhatsApp. We knew the teams had been cut back and we had to contribute to the SUS, which was facing a shortage of PPE at the time. Collaborating in that monitoring was a way to reduce need for teams to circulate through the territory and thus reduce the likelihood their personnel contracting the virus.

As already mentioned, in three territories, PHC participation in support of these mobilisa-
One user said: sanitary measures and restrictions were relaxed. A few people, the family.

If you go into the favela, you will even feel embarrassed to be wearing a mask.

Resources including the District Health Council (Conselho Distrital de Saúde) and the Local Management Collegiate (Colegiado Gestor Local) were listed as important bodies for public participation in Catumbi and Jacarezinho. In Catumbi, the functioning of residents’ associations was hampered by the pandemic; nonetheless, the FC and local leaders coordinated to collect and distribute basic food baskets and support users’ travel to facilities in the social assistance system.

In Jacarezinho, LabJaca, a data observatory, was set up to give visibility to pandemic-related data on the neighbourhood, including the number of cases and deaths. It was clear that the active position taken by all kinds of social actors, particularly PHC personnel, councils and community leaders, was fundamental in supporting measures to control the pandemic, especially in restricting contacts and improving social distancing.

LabJaca is a laboratory for research, training and production of data and narratives about favelas and peripheries, because official data did not reflect realities in the territory. The main objective was to give due value to knowledge coming from favelas themselves, so as to inform public policies to promote these territories and thus generate social impact. Using citizen-sourced data generated in partnership with residents and institutions, it tracks action to meet the community’s real demands, as well as monitoring local development, so as to propose ways to reverse the present situation.

One interviewee reported that the Anthidio Dias da Silveira FC launched an online information panel in April 2020. The data demonstrated, among other things, the number of positive test results at the unit and of deaths recorded by CHWs, who collected information from death certificates in their areas. This data differed from what was posted on the official municipal health department panel, which months later also ceased to be public. The FC was asked to discontinue its panel and use only the official data posted by the health department. On that occasion, groups from some favelas, including LabJaca, took over the panels that had been developed and continued the count recorded in their communities.

The initiatives of groups organised in the favelas are considered to expand the concept of
social oversight – what here is called social activism – by proposing action integrated with the PHC service to address this context of health emergency centrally in a new way of collaborating with health surveillance, promotion and communication.

Although these territories entail great social vulnerability and a marked absence of public authority, which was even more accentuated in the pandemic, they differ clearly by geographical location. In the Rocinha, in Rio’s south zone, the area with the highest HDI in the municipality, the potential is more evident, while in Jacarezinho, in the suburbs, what predominates is neglect:

Living in Rocinha is difficult. It’s a city within a city. I like it here – some points, others not. It has practically everything, commerce, transport, ease of movement, food... The groups make a difference, they got together. Today we have a huge collection of organised groups; there are more than a 150 that help not only our community, but others. And they do a lot more than any government.

Jacarezinho is never news, unless there’s a massacre, a police operation. There’s a lot lacking in the community, there’s a football field in an abandoned factory... the only free space we have. You have policies brought in on an emergency basis, but you don’t have an ongoing policy that brings people to participate actively in public, political life.

The role of Primary Health Care in this context

Health facilities were the only public services that continued operating throughout the pandemic in the four research fields. The exception was the emergency care unit (Unidade de Pronto Atendimento, UPA) in Manguinhos, which serves residents of Manguinhos and Jacarezinho and operated in precarious conditions in 2020, then was closed for a time during the pandemic.

PHC remained active, serving mostly users with milder flu symptoms. It continued offering antenatal care and care for people in treatment for tuberculosis, leprosy and HIV; and dispensing medication for non-communicable chronic diseases, initially in a scenario where personal protective equipment was in short supply and work processed had to be remodelled. A doctor described the change in the unit’s profile:

The FC started to receive a lot of urgent cases, like a small UPA providing care for people the team already knew, had a bond with.

Most workers reinvented their work processes, given the more than 30 technical notes from the municipal health department and the lack of guidance from the Ministry of Health:

We held several meetings about flow. We had to change the whole care portion during COVID. One from each team took part. We discussed it in each team and then went back to the group, and not everyone managed to adapt to these new realities.

In various countries, PHC can be seen to modify the user’s risk of worsening, underlining the importance of its role and that that role must be strengthened to allow proper monitoring and resolution of cases that can be monitored at home and at a PHC facility. Ideally, PHC should include health surveillance, with testing and contact tracing, as well as supporting isolation measures and giving guidance on protection measures.

Another care tool that became established was tele-monitoring of users attending the FC, in order to monitor signs of worsening and to offer local people better guidance. Accordingly, even though the staff was smaller, from personnel being off sick or in a risk group, a new strategy emerged in the workflow and many people were strengthened by these connections, as it was a time when mental health issues were aggravated. Many users needed someone to talk to about their anxieties, which was made possible by telephone contact with practitioners from different professions. For one of the workers, however, tele-monitoring meant moments of anxiety and anguish:

When I took on this responsibility, I had no idea it would be so complex. I started contacts in the morning, but there was no time set limit: I received messages all day, at night and at weekends. This was bad for my health, because I got emotionally involved with the many stories of loss and suffering.

Conclusions and other considerations

In response to the devastating scenario of the pandemic in Brazil and the absence of protective measures by government agencies, organised groups acting in an integrated manner with PHC teams in the surveyed territories were found to have engaged in social activism and initiatives. The responses from favelas, which took action to identify and support their most vulnerable residents by distributing basic food baskets and offering personal protection and hygiene material, achieved positive impact in combating the effects of the pandemic.
The results show that despite the pandemic, the absence of the State and the violence in the research territories, there was a response from social activism in these favelas. The PHC teams joined in a number of these actions to address mounting unemployment, hunger and illness, in a scenario of worsening health needs and social vulnerability.

PHC was strategic, because it stayed open in the territories throughout the pandemic and the FCs were the main public facility supporting the local population. In addition to attending to health problems, the worsening poverty and increased vulnerability of the territories had become a health need to be met by PHC. In this regard, the FCs’ collaboration with the social mobilisation initiatives by the organised groups proved a powerful and necessary partnership, as a result of the various kinds of exchange that took place in a two-way relationship – sometimes the FC personnel the actions of the collectives and, at other times, they sought the community’s help to meet demands from the health teams. Facilitating a closer relationship with, and referring users to, social assistance services has become another fundamental activity in meeting the new demands.

Another important factor observed was the episodes of armed violence inside some territories, despite the Supreme Court’s prohibiting police raids.

In conclusion, the context experienced by the vulnerable territories that are the study object of this article produced complex confrontations that point to new practices that are to be valued. PHC is strengthened by the territorial-based organisation of which it forms part, with all its diversity and scope for recognising organised groups and social activism.

**Collaborations**

AC Gutiérrez and GWS Campos: conception, data production and analysis, fundraising, field research, methodology, research management, drafting and final review of the article. MS Cunha, MP Mattos, PS Costa, ROL Silva, ACSR Pereira: conception, data production and analysis, field research, methodology, research management, drafting and final review of the article. Adilson Rocha Campos and Cyntia Amorim Guerra: drafting and final review of the article.

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