

ENSAIO ESSAY

Community participation in the fight against COVID-19: between utilitarianism and social justice

Participação comunitária no enfrentamento da COVID-19: entre o utilitarismo e a justiça social

Participación comunitaria frente a la COVID-19: entre el utilitarismo y la justicia social

José Patrício Bispo Júnior ¹ Marciglei Brito Morais ¹

doi: 10.1590/0102-311X00151620

Abstract

This essay aims to discuss the foundations and possibilities for community participation in the fight against COVID-19. The first part discusses the meanings of community, defined according to geographic, aggregate-interest, or epidemiological criteria. In the context of the pandemic, none of the three perspectives can be considered alone. The essay discusses the need to link different approaches in order to produce socially contextualized health interventions. Next, the authors present the four main models in the international literature that provide the basis for community participation practices in various countries. The analysis of community participation in the context of COVID-19 uses conceptual systematization based on two meta-narratives: utilitarian and social justice. The utilitarian perspective involves measures to restrict social contact. Participation is thus understood as collaboration in implementing measures that contribute to controlling the problem. The social justice perspective especially addresses the social determinants of health and reduction in social inequalities. The approach focuses on community empowerment and the search for solutions to the social and economic problems that determine the spread of COVID-19 and other diseases. The essay concludes on the peculiarities and importance of each approach. Community participation in the fight against COVID-19 should consider the emergency contexts to strengthen the health system and the defense of the social protection system and democracy.

Community Participation; COVID-19; Health Systems; Health Policy; Social Determinants of Health

Correspondence

J. P. Bispo Júnior Núcleo de Epidemiologia e Saúde Coletiva, Instituto Multidisciplinar de Saúde, Universidade Federal da Bahia. Rua Hormindo Barros 58, Vitória da Conquista, BA 45029-094, Brasil. jpatricio@ufba.br

¹ Instituto Multidisciplinar em Saúde, Universidade Federal da Bahia, Vitória da Conquista, Brasil.



Introduction

COVID-19 is considered this century's greatest global health problem ¹ and is challenging scientific and political authorities to identify the most adequate clinical, epidemiological, economic, and social approaches to the disease. Experts agree that there is insufficient scientific knowledge on the novel coronavirus ^{1,2,3}. In this context, uncertainties prevail as to the actions and policies to be used to contain and mitigate the epidemic ².

Two main strategies have been adopted in the fight against COVID-19. One relates to the structuring and expansion of the health systems' hospital care. Given the high pathogenicity and virulence of SARS-CoV-2, governments in various countries seek to expand the supply of clinical and intensive care beds dedicated to severe cases of COVID-19 and thus save the lives of patients with complications from the disease.

The other priority strategy involves restriction of social contact. This strategy is more comprehensive, involving not only the health system component, but dealing with broader action by society to reduce circulation and contact between persons and thus slow the incidence of the disease and delay the plateau in the epidemic curve. This decreases the exponential demand for healthcare and seeks to minimize the mortality resulting from the lack of care generated by the overload on health systems ⁴. The most widely recommended measures to restrict social contact are social distancing in the general population, isolation of confirmed and suspected cases, and quarantine of contacts ⁵.

Since restriction of contact depends much more on awareness-raising and involvement of the population than on professional interventions, it requires community participation to implement the measures effectively.

The population's involvement has always proven to be a basic element in outbreaks and epidemics ⁶. Given the risk of spread of new or known diseases, health systems frequently rely on mobilizing the population to help contain or mitigate health problems. In recent times, society's mobilization has been used in various countries to control such diseases as influenza A (H1N1) ⁷, ebola ⁸, dengue ⁹, and Zika ¹⁰, among others.

Despite consensus on the importance of involving citizens in health production processes ¹¹, the understanding of the nature of such participation differs widely ¹². Community participation can take various connotations, since there are many possible definitions of "community" and various models for "participation" ⁶.

The analysis of community participation in the fight against COVID-19 thus requires knowing the model of participation used and the space occupied by the population in the social and health systems. Such conceptual demarcations are relevant, given the risk of idealizing community involvement ¹³ and the development of unrealistic expectations towards participation in an adverse political and social scenario ¹⁴.

The article aims to discuss the basis and possibilities for community participation in the fight against COVID-19. The first section addresses the geographic, interest-group, and epidemiological meanings of community and the importance of an in-depth understanding of community in the fight against COVID-19. Next, we present four models of community participation discussed in the international literature. We then analyze community participation in the fight against COVD-19, based on the perspectives of utilitarian participation and participation for social justice.

The meanings of community in the fight against COVID-19

Communities can be defined differently. The most widespread and well-known approach to community is geographic. However, various authors cite the limitation and inadequacy of the geographic approach to community ¹⁴. In addition to demographic limits, communities can also be defined by social and economic characteristics and values or traditions ¹⁵.

The international literature ^{14,16,17} has identified three meanings of community that are more widely used in health. The first is demographic, characterizing community as a group of persons living in a defined area such as a specific neighborhood or locality and sharing the same processes of territorial organization. The second definition involves a group of persons that share the same interests

and identities. In this approach, the meaning of community has less to do with territory, since persons can have common identities and affinities while living in different neighborhoods, cities, or countries. The third definition relates to community as a target population or risk group. This definition is the basis for the epidemiological view of community and may or may not be linked to territory.

In the disease control setting, as with COVID-19, the most commonly used approaches are geographic and epidemiological. However, these approaches focus little attention on other characteristics such as sense of belonging, identity, and traditions, which can make the difference in health promotion or prevention activities 18. Atkinson et al. 19 point out that geographic proximity is not always equivalent to social cohesion and shared interests, particularly where there are imbalances in the availability of resources, cultural heterogeneity, ethnic tensions, itinerant populations, or predominance of individualist values. Many of the difficulties in activities aimed at community participation in health are due to inadequate and narrow understanding of community 18.

In Brazil, the term "community" has become popular for referring to poor and marginalized populations, normally residents of favelas and risk areas. The replacement of the term favelados (~ slumdwellers) with "community residents" might suggest a decrease in the stigma and prejudice attached to favela. However, its exclusive use for "needy" communities may also denote a kind of reverse prejudice, as if members of the middle and upper classes were not also "communities".

An in-depth understanding of community is essential for the fight against the pandemic. None of the community perspectives presented here - geographic, identity, or epidemiological - can be considered alone. Given the high transmissibility of SARS-CoV-2 and the difficulties in controlling COVID-19, the three approaches need to be interconnected in order to allow technically effective and socially backed mobilizations and interventions. The communities' heterogeneity and dynamics also need to be acknowledged. Even if they express shared socially, economically, and/or culturally shared characteristics, communities are not uniform and their members experience unequal relations, with tensions and clashes in their positions. Thus, community participation strategies will always be influenced by this heterogeneous nature and moments of greater or lesser affinity of interests.

Models of community participation in health

The term "participation" also has multiple meanings and can reflect diverse perspectives and approaches. Citizens' involvement in health systems has been widely studied. The Brazilian and international literature offers various typologies and models that illustrate and support possibilities and levels of participation. These theoretical frameworks present hierarchical approaches, with levels of involvement ranging from passive participation to the population's empowerment and power-sharing.

Next, we present four important theoretical frameworks underlying community participation in health systems around the world and that are used in this essay to analyze community participation in the fight against COVID-19. Although there are other important references for participatory models used in various contexts, we selected these four as the best basis for the possibilities and approaches for participation in the current pandemic.

The forerunner and most widely cited model of participation was published by Arnstein in the 1960s 20. The author illustrates eight types of participation using a "ladder" model, with the most advanced types corresponding to the highest rungs. Arnstein's ladder is divided into three levels that include the eight types of participation. The lowest level, "nonparticipation", includes manipulation and therapy. The intermediate level corresponds to tokenism, consisting of informing, consultation, and placation. The most advanced level, citizen power, involves partnership, delegated power, and citizen control. Among other aspects, the Arnstein ladder model features power-sharing as the most advanced and desirable level of participation.

Another important and widely cited model is called the continuum of community participation ^{21,22}. This model systematizes three ways by which communities participate in health action: community mobilization, collaboration, and community empowerment. To analyze the depth of community participation, the levels of participation were related to the scope of influence, concept of health, and relations established between communities and professionals (Box 1).

Box 1

Balance of power and continuity of community participation.

Level	Scope of influence	Definition of health	Balance between communities and professionals
Community mobilization	Physician	Absence of disease	People follow health professionals' recommendations.
Collaboration	Health services	Physical, mental, and	Communities contribute with donations, time, and/
		social wellbeing	or help with services provision. Needs and actions
			defined by the professionals.
Community empowerment	Community	Human condition	Planning and conduction of health activities
	development		by communities using professionals with
			resources and facilitators.

Source: developed by Rifkin 21 and adapted by George et al. 22.

In this sense, community mobilization proposed only with purpose of curing or avoiding a disease and the population's participation are limited to following health professionals' instructions. The collaboration approach emphasizes the health system's best performance, and community participation is performed with the development of actions or services provision by community members. Meanwhile, community empowerment aims to promote community development to change the population's living conditions with power-sharing between health systems and the population.

The theory of change model was developed by Popay ²³ and backs the participatory practices in the United Kingdom's National Health Service. In the proposed model, participation, differentiated according to its objectives, consists of four approaches: informing; consultation; coproduction; and community control. As illustrated in Figure 1, the Popay diagram signals that the most basic levels of participation, such as informing or listening, are able to promote results in healthcare terms. Broader results are achieved with coproduction and community control. From the author's perspective, participatory practice should progress to the extent that communities have greater control over the decisions affecting their lives in order to improve their health and reduce inequalities.

The fourth model of participation was developed by Brunton et al. ¹⁵, based on a systematic review of community participation models. The authors systematized a theoretical framework with two meta-narratives of community participation in health systems: utilitarian and social justice. The utilitarian perspective seeks the population's involvement with the specific purpose of disease control or implementation of programs. It is a kind of instrumental participation, targeted to improving the efficacy of interventions and with little capacity to impact living conditions. Meanwhile, the social justice perspective is an expanded approach to participation with a focus on community empowerment and development. Social and structural changes are at the center of social justice concerns. The model assumes that communities mobilize and are supported to participate, negotiate, influence, and control health decisions and actions.

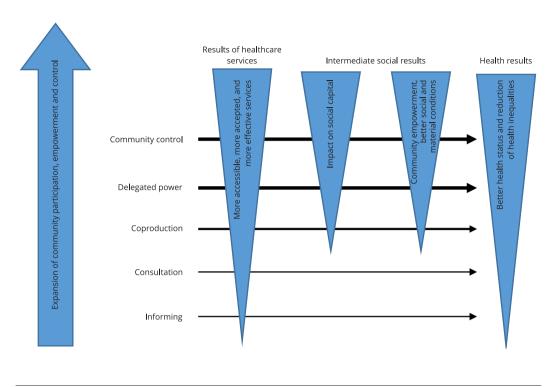
Community participation in the fight against COVID-19

To reflect on community participation in the fight against COVID-19, we will use the conceptual system elaborated by Brunton et al. ¹⁵, based on the utilitarian and social justice perspectives, and discuss these two approaches correlated with the other theoretical frameworks presented here ^{21,23}.

The utilitarian perspective involves actions targeted to the health problem's mitigation and suppression and to emergency support during the pandemic. The population's participation is thus essential for implementing measures such as social distancing, isolation of cases, and wearing masks. It is impossible to obtain satisfactory results in decreasing circulation of the virus without the population's involvement. In this context, participation assumes the sense of collaboration (Box 1) or copro-

Figure 1

Models of community empowerment and involvement for improvement of health.



Source: Popay 23.

duction (Figure 1), according to the models by Rifkin ²¹ and Popay ²³. That is, community participation involves performing actions that contribute to the problem's direct control.

Even though it is a well-known and widely used instrumental perspective, its development does not depend only on the population's will or awareness. Community involvement is determined mainly by socioeconomic and structural conditions. Social distancing in peripheral communities living with dense urban crowding demonstrates how difficult it is to operationalize. Likewise, it is obviously impossible to isolate persons, confirmed or suspected cases, when they live in precarious housing, where entire families share a single room with precarious access to water and hygiene products.

As highlighted by Werneck & Carvalho ¹, the COVID-19 epidemic is unfolding in Brazil in a context of the population's extreme vulnerability and budget cuts to social policies. Thus, community participation in utilitarian collaboration faces obstacles from adverse social conditions.

As occurs with most infectious diseases, COVID-19 shows greater capacity to spread and worse case-fatality in poor communities ²⁴. The disease is known to have been introduced in Brazil through the middle class and segments of society with more purchasing power. However, its spread has continued with heavier impact on lower-income Brazilians. Brazil's worsening social inequality shows that community participation needs to evolve from collaboration to empowerment.

Although it is not possible to do without utilitarian participation to control the pandemic, the social justice approach proves desirable by especially addressing social determinants, health improvement, and reduction of inequalities. The social justice perspective creates a sense of community appropriation of local problems and encourages communities to contribute to the development of concrete strategies by which they can improve their health conditions ²⁵. Thus, the approach to COVID-19 should involve not only the development of actions to control circulation of the virus, but especially the search for solutions to social and economic problems that determine the spread of this and other diseases.

This context also calls for reflection on the relevance of community participation in the post-pandemic period. The catastrophic harms from COVID-19 will extend beyond the eventual downturn in the pandemic curve. Unemployment, hunger, psychological problems, violence, and increases in other diseases are among the expected consequences ^{2,26,27}. Thus, participation focused on community empowerment proves to be a vigorous strategy for influencing the direction of social and health policies with a view towards social justice.

Another key aspect is institutionalized participation in the sphere of the Brazilian Unified National Health System (SUS). Health councils throughout Brazil have been marginalized in the decision-making and follow-up of policies in the fight against COVID-19. States and municipalities have established crisis committees and/or commissions to support the executive branch in the decision-making process. However, civil society's representation in these committees consist most of the industrial and business sectors, with limited representation of popular and social segments. This also undercuts the health policy decision-making nature attributed legally to the councils.

As bodies that strengthen democracy ²⁸, Brazil's health councils are a productive tool for fomenting participatory practices and citizen education, with the capacity to promote the population's empowerment in the medium and long term ¹². We thus emphasize three important characteristics of the health councils: (a) equitable composition; (b) decision-making role; and (c) responsibility over the follow-up of economic and financial aspects of health management. These attributes accredit them as democratic bodies, representative of society's interests and responsible for deciding on and monitoring health policies related to COVID-19.

The health councils' composition includes representatives of users, health professionals, administrators, and public and private healthcare providers. This architecture allows the aggregation and integration of diverse segments involved in the health production process. The councils' composition includes a technical and scientific component, with participation by health professionals and providers, a political and organizational component based on administrators' representations, and a social and democratic component with involvement of popular segments and civil society. The councils are thus mechanisms for democratic expansion and innovation ¹² and legitimate bodies for aggregating interests to deal with the pandemic's issues.

The decision-making role is clearly established under the legal framework of the SUS, whereby the councils are responsible for deciding on health policies and the executive branch approves their decisions ²⁸. Thus, the established body for deciding on policies and actions in the fight against COVID-19 is the health council in each municipality or other level of governing. Shifting the decision-making role to the crisis committees is an affront to the institutional framework of the SUS, undermining the principle of community participation. This de-legitimation may also have repercussions that extend beyond the pandemic. Usurping the health councils' decision-making role tends to trigger processes of social demobilization and exacerbation of the country's ongoing democratic deficit.

Finally, we emphasize the issue of attribution in the follow-up of economic and financial matters. The health councils are the bodies responsible for quarterly assessment and approval of the budget outlay in the corresponding sphere of government. According to Kohler & Martinez ²⁹, accountability is an essential requirement for good governance. The authors further emphasize that monitoring accounts by the health councils allows increasing the accountability of the SUS and requires greater decision-making transparency. Given the need for expanding the network of care for persons with COVID-19, governments have had to provide new services, often turning to emergency purchase of supplies and equipment and hiring of services in the private system and with third sector organizations. In this context, the health councils need to be empowered and strengthened to exercise their oversight of government accountability.

Final remarks

With different objectives and scope, the two participatory approaches discussed here are indispensable in the fight against COVID-19. The utilitarian perspective proves to be adequate and timely for mitigation and suppression of the disease, although it cannot be developed in a fragmented way, decontextualized from the social reality. The social justice approach requires understanding that community participation is a complex, uncertain, and amorphous social process, but which cannot lose sight of the primacy acting on living conditions and their determinants.

Finally, community participation in the context of COVID-19 should consider three interconnected contexts. The first has an emergency basis, seeking to control the problem, guaranteeing adequate care for cases and economic safeguards for families to survive the crisis period. The second involves the need to value and strengthen the SUS to continue to be consolidated as a public, universal, and comprehensive health system. The third and most daunting challenge for community participation in Brazil is to change the country's economic and political matrix, reclaiming the social protection system and society's project for democracy.

Contributors

J. P. Bispo Júnior participated in the study's conception, analysis of the information, writing of the manuscript, and approval of the final version. M. B. Morais participated in the analysis of the information, critical revision of the manuscript, and approval of the final version.

Additional informations

ORCID: José Patrício Bispo Júnior (0000-0003-4155-9612); Marciglei Brito Morais (0000-0003-1502-1827).

Acknowledgments

The authors wish to thank Luciano Nery Ferreira, professor at the State University of Southwest Bahia (UESB), for his valuable contributions to revision of the text.

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Resumo

O presente ensaio objetivou discutir os fundamentos e possibilidades da participação comunitária para o enfrentamento da COVID-19. Na primeira parte, são discutidos os sentidos de comunidade definidos por critérios geográficos, de agregação de interesses ou epidemiológicos. No contexto da pandemia, reflete-se que nenhuma das três perspectivas podem ser consideradas isoladamente. Foi discutida a necessidade de articulação das diferentes abordagens a fim de se prover intervenções sanitárias socialmente contextualizadas. Em seguida, são apresentados os quatro principais modelos teóricos presentes na literatura internacional que fundamentam as práticas de participação comunitária em diversos países. Para a análise da participação comunitária no contexto da COVID-19 foi utilizada a sistematização conceitual fundamentada em duas metanarrativas: a utilitarista e a da justiça social. A perspectiva utilitarista envolve ações direcionadas às medidas de restrição do contato social. Nesse sentido, a participação é entendida como colaboração na execução de ações que contribuam para o controle do agravo. A perspectiva da justica social aborda sobretudo os determinantes sociais da saúde e a redução das desigualdades sociais. Trata-se de abordagem voltada ao empoderamento comunitário e à busca de soluções para os problemas sociais e econômicos determinantes da disseminação da COVID-19 e de outras doenças. Conclui-se sobre as peculiaridades e a importância de cada uma das abordagens. A participação comunitária no enfrentamento da COVID-19 deve considerar os contextos emergencial, de fortalecimento do sistema de saúde e de defesa do sistema de proteção social e da democracia.

Participação da Comunidade; COVID-19; Sistemas de Saúde; Política de Saúde; Determinantes Sociais da Saúde

Resumen

El objetivo del presente ensayo fue discutir los fundamentos y posibilidades de la participación comunitaria para el combate de la COVID-19. En la primera parte, se discuten los sentidos de comunidad, definidos por criterios geográficos, agregación de intereses o epidemiológicos. En el contexto de la pandemia, se refleja que ninguna de las tres perspectivas puede ser considerada aisladamente. Se discutió la necesidad de una coordinación de los diferentes planteamientos, a fin de proporcionar intervenciones sanitarias socialmente contextualizadas. En seguida, se presentan los cuatro principales modelos teóricos presentes en la literatura internacional que fundamentan las prácticas de participación comunitaria en diversos países. Para el análisis de la participación comunitaria en el contexto de la COVID-19, se utilizó la sistematización conceptual fundamentada en dos objetivos narrativos: el utilitarista y el de la justicia social. La perspectiva utilitarista implica acciones dirigidas a las medidas de restricción de contacto social. En este sentido, la participación es entendida como colaboración, en la ejecución de acciones que contribuyan al control de enfermedades. La perspectiva de la justicia social aborda sobre todo los determinantes sociales de la salud y la reducción de las desigualdades sociales. Se trata de un planteamiento dirigido al empoderamiento comunitario y a la búsqueda de soluciones para los problemas sociales y económicos determinantes de la diseminación de la COVID-19 y de otras enfermedades. Se concluye con las peculiaridades y la importancia de cada uno de los planteamientos. La participación comunitaria en el combate a la COVID-19 debe considerar los contextos de emergencia, de fortalecimiento del sistema de salud v defensa del sistema de protección social, así como de la democracia.

Participación de la Comunidad; COVID-19; Sistemas de Salud; Política de Salud; Determinantes Sociales de la Salud

Submitted on 03/Jun/2020 Final version resubmitted 04/Jul/2020 Approved on 07/Jul/2020