

Civilian health surveillance, population studies and participation

Vigilância civil em saúde, estudos de população e participação popular

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ABSTRACT In the mid-1990s, Victor Valla proposed to incorporate the population participation in the practice of health surveillance, through Paulo Freire's popular education. This counterpoint to traditional surveillance practices, called civil health surveillance, added to the expanded concept of health, and has a strong connection with the critical perspective of Epidemiology as a means to understand the dialectical relationship between social classes and their lived spaces. The practice of civil surveillance aims to overcome essential gaps left by traditional methods of public health investigation. It includes a lack of attention to socio-cultural contexts, the construction of risk located only in the individual, and the representation of public health agendas that privilege and pathologize certain behaviors. This paper discusses the concept of civil health surveillance, the locus of discussion of population studies in the reification of the role of the contextual effect in explaining the social production of health and the incorporation of popular participation in health surveillance as an element of social transformation. The deepening of this discussion allows a participatory construction of new health models focused on the effective reduction of health inequities and, consequently, the effective universalization of the right to health.

KEYWORDS Health surveillance. Civil health surveillance. Popular education and health. Popular participation.

RESUMO *Em meados dos anos 1990, Victor Valla propôs a incorporação da participação da população à prática da vigilância em saúde, por meio da educação popular de Paulo Freire. Esse contraponto às práticas tradicionais da vigilância, nomeadas vigilância civil da saúde, somam-se à concepção ampliada de saúde, e possuem forte ligação com a perspectiva crítica da epidemiologia enquanto meio de compreender a relação dialética entre classes sociais e seus espaços vividos. A prática da vigilância civil pretende superar lacunas importantes deixadas pelos métodos tradicionais de investigação em saúde pública, como falta de atenção aos contextos socioculturais, construção do risco localizada somente no indivíduo e representação de agendas de saúde pública que privilegiam e patologizam certos comportamentos. Nesse sentido, o presente trabalho debate o conceito de vigilância civil da saúde, o locus de discussão dos estudos de população na reificação do papel do efeito contextual para a explicação da produção social da saúde e a incorporação da participação popular à vigilância em saúde como elemento de transformação social. O aprofundamento dessa discussão, no limite, permite uma construção participativa de novos modelos de saúde concentrados na redução efetiva das iniquidades em saúde e, conseqüentemente, universalização efetiva do direito à saúde.*

PALAVRAS-CHAVE *Vigilância em saúde. Vigilância civil da saúde. Educação popular e saúde. Participação popular.*

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Introduction

The publication of the Statutory Health Laws (Laws nº 8.080, September 19, 1990; and nº 8.142, December 28, 1990) established the doctrinal and operational principles of the Unified Health System (SUS) including ways of popular participation in the health system's collegiate management. This is an important achievement for social and human rights in Brazil. Health surveillance is also considered one of the essential functions of public health. This model of care is based on the integration of actions comprising the health situation of the country's population beyond institutionalized spaces of the healthcare system¹.

In Brazil, health surveillance is considered a continuous and systematic process of collecting, consolidating, analyzing, and disseminating health-related data for planning and implementing public policies, including regulation, intervention, and action on health determinants to protect and promote the population's health, preventing and controlling risks, illnesses, and diseases². Operationally, it presents the components of epidemiological surveillance, health care and health situation surveillance, environmental surveillance, worker health surveillance, and sanitary surveillance³.

Its work processes include the production of analyses to support setting priorities and strategies, monitoring and evaluating public health actions that regularly and systematically can be developed in public and private healthcare services, laboratories, study, work environments, and in the community itself⁴.

On the 12th July 2018, the National Health Council (CNS) created the National Health Surveillance Policy (PNVS), Resolution nº 588, to guide health surveillance actions within the three levels of SUS management⁵. The PNVS is a State public policy, universal, transversal, and guiding the health care model within the territories. For its effectiveness, needs strengthening and articulation with other health system agencies⁶.

Non-institutional articulation strategies, however, are not distinguished. Non-institutional articulation strategies, in opposition, are not distinguished. In the mid-1990s, amidst the historical criticism of traditional health surveillance, Victor Vincent Valla developed the concept of civilian health surveillance as a way to include popular participation in health surveillance through processes such as knowledge sharing. The approach, based on Paulo Freire's concept of popular education, is a method for building a new social awareness⁷. Thus, Valla's idea⁸ was based on accomplishing "a daily epidemiology developed by popular sectors alongside professionals interested in the theme".

Accordingly, this essay aims to discuss the concept of civilian health surveillance, the locus of the population studies debate, in reifying the role of context effects so to explain the social production of health and incorporation of popular participation in health surveillance as a means of social transformation.

Population studies and the social production of disease

The population needs and conditions of health can only be measured or understood with a proper knowledge of its size and characteristics. Public health planning is only possible when the target population composition is known in order to identify who are the most vulnerable and then establish the priorities actions to be implemented. In its way of organization, public health brings conceptual and theoretical aspects focused on health surveillance actions, with biological and individual dimensions¹⁰. Therefore, certain individual information such as gender and age groups and contextual factors such as education and living and housing conditions are essential for successful health actions.

In Brazil, there is a striking complexity in the epidemiological scenario: there

is a polarization effect, in which regional inequalities end up marking important differences between the different federative entities in the country¹¹. Faced with the challenge of having a single, integrated, and universal health system, an alternative model of healthcare was idealized to articulate and integrate the appropriate actions to the specificities of the health situation in each territory. Thus, it relied on the integration of expertise from different areas of knowledge, such as medicine, geography, applied social sciences, and statistics^{12,13}. It is important to emphasize the place of demography as an applied social science that, in addition to the method, uses the social contextualization of quantitative changes in the pattern and level of social indicators. Demography is interested in the characterization and understanding of population dynamics, that is, how populations change in response to fertility, mortality and migration trends¹⁴. Given this, the analysis of the population structure at present and in the future requires a consideration of the demographic components over time. Therefore, the importance of demographic characteristics in planning by public health professionals is reinforced¹⁵. This includes characteristics that encompass the set of social norms and conventions as well as the structure and organization of social classes¹⁶.

As a matter of fact, the assessment of health and disease through measuring mortality and morbidity is a central aspect of demographic disciplines. The size, composition, and distribution of the population are key attributes to help in understanding the level of access and utilization of health services as well as the morbidity and mortality profile of sub-populations. Therefore, health demography considers the aspects of health on two levels – individual and population. The intrinsic relationship between the individual and the population levels is what gives the production of health and disease its procedural rather than watertight character.

Social determinants of disease in the context of populations

The connection between a person's social status and health outcomes was first made about 40 years ago in a set of reports from the Whitehall Studies in England, conducted among civil servants of a state-owned bank. At that time, when comparing strata of workers, all with relative stability, but with distinct attributions and functional status (especially salaries and certain labor benefits), it was observed that the greater social and labor advantages, the longer life expectancy and the better health of the workers¹⁷. This has become known as the social gradient, and it refers not only to income, but to a set of socioeconomic factors, and the way in which these factors grant people greater autonomy and control over their lives, including the perception of social position. This is a pioneering study in the development of social epidemiology. Some years later, these factors were called social determinants of health¹⁸. Factors such as income, formal education, social class, and work were elaborated on so to build a complex model of causality that included individual factors (modifiable or not), collective and contextual factors until today widely used to explain the origins and natural course of diseases^{19,20}.

Internationally, social determinants in health have been considered an emerging issue in public health. In Brazil, this discussion is not recent, and there are several authors with a vast contribution to this debate with some important conceptual aspects to the scope of this rationale²¹. The main one refers to the different social sciences approaches by the public health. Initially, the discussion of epidemiological data, in a less comprehensive way, led to the creation of theoretical models including social aspects, but disconnected from each other, and were addressed as risk factors in the same level of lifestyles, consumption pattern, or non-modifiable factors such as sex, age,

and race/skin color. This approach is known as the social determinants of health model²². The most recent studies define five dimensions: economic stability; education; social and community context; health and health care; and environment and neighborhood²³. Each of these reflects a number of key issues that comprise the underlying factors. For example, economic stability covers employment and poverty, social and community context covers discrimination and social cohesion, and environment covers spatial organization, urbanization, and crime and violence.

Initially, for the construction of this theoretical model, individual and collective characteristics were considered through explanatory categories for the occurrence of health problems: the fixed or biological determinants, such as age and sex; the economic and social determinants, such as position, social stratum, and poverty; the environmental ones, such as air and water quality; the lifestyle ones, including diet, physical activity, smoking, and alcohol; and more global aspects, such as access to health services²⁴. However, in the words of Garbois et al.²⁵, in the limit, “the notion of social determinants of health reinforces the polarity established between the biological being and the social being”, and the analysis of their health situation – if such a term is suitable – is analyzed by professionals in the hard skill in health care, such as doctors, nurses, and nutritionists; and by professionals in the social field, such as psychologists and social workers, as if such elements were disconnected.

Criticism of this model brought the need for a new approach which was called social determinism, in a clear attempt to overcome the fixed model of determinants. This paradigm, in turn, comprises a set of elements, structure and social cohesion, which are dynamic by definition. Thus, it considers not only the indicators and the models of causality, but also how they change and are changed by the daily relations and the political and economic conjuncture²⁶. It is worth noting that this notion is strongly

marked by references to historical materialism, with emphasis on the processes of production and social reproduction²⁷.

The tension caused by the conflict between these two paradigms has been the target of criticism for decades. A striking example is the critical analysis by Nogueira²⁸ to the report on social determinants of health released by the World Health Organization (WHO) in 2008. In this official document, the WHO includes social indicators in theoretical models about the health-disease process. However, it discards any contribution from social and political sciences, treating the determinants as just another element to be considered for the explanation – but not intervention – of international public policies. Although it emphasizes the need to reduce health inequalities around the world through a broad set of social policies, the report ends up explaining the contribution of epidemiology on the metrics of these indicators, however, it presents little on how to deal with the pronounced local differences between classes and social contexts²⁹.

At the time, it is worth saying, this report represented a backward step to the discussion coined around the 1970s by the Latin American socio-medical approach of social determinism in health³⁰. This report, it is worth mentioning, represented, at the time, a backward step to the discussion coined around the 1970s by the Latin American medico-social current of the social determination of health³⁰, bringing a fragmented ‘social’, insufficient to analyze the social changes of contemporaneity, especially in countries with a deep social heterogeneity, such as Brazil³¹.

The paradigm shift from determinants to determinism is undoubtedly an advance in the study of non-biological aspects of the health-disease process. This is due to the fact that determinism assumes a new focus and explanatory reference framework of the relations between the various levels – individual, collective, community, and contextual – and the health situation³¹. As a result, the possibility of intervening in living conditions increases

substantially, whether through programs or through more consolidated and long-term policies. In this regard, Rocha and David³² highlight that, in the definition of public policies, given their nature of dispute, the adoption of one or another perspective can support (or not) a more or less focused action, depending on how one structures these political implementation processes.

The social determinism of the health-disease process is translated, therefore, into the conditions in which people are born, grow, live, work, and age. These circumstances are defined by the distribution of income, power, and resources at the global, national, and local levels, affecting a broad set of risks to health and quality of life²⁰. Examples of determinism dimensions are: availability of resources to meet daily needs; access to educational, economic, and employment opportunities; access to health services; availability of community facilities and resources for social support and opportunities for recreation and leisure activities, public safety, social support, exposure to violence, and social disorder; and socioeconomic conditions (such as concentration of wealth and absolute poverty)²¹.

Public policies and the social dimension of life

In Brazil, the democratization process of health, after the 1988 Constitution and the subsequent creation of SUS (Brazilian Unified Health System), induced intersectoral public policies to adopt a broad conception of health-care, with health promotion, disease prevention, treatment, and rehabilitation actions³³. To make these feasible, it is necessary to consider the possibility of eradicating social inequities by adjusting health priorities according to the need for attention to different local contexts still marked by poor accessibility to material and immaterial goods and social opportunities.

In this sense, Latour³⁴ advocates a new approach to the social, which understands it as

a point of arrival, of convergence, and not as a point of departure. This means that natural phenomena (including the processes of illness) should be analyzed from the social perspective, and not the other way around. For this, besides quantifying reality by means of indicators, it is necessary to analyze it subjectively; and to understand the health-disease process, based on this qualitative approach³⁵.

In 2006, the National Commission on Social Determinants of Health was created with the objective of promoting studies on social determinants and advancing in their causal mechanisms to recommend policies to promote health equity and tackle health inequities³⁶.

Popular participation and participatory surveillance

It is important to remember that, from the late 1970s and early 1980s, the health field went through an important moment in Brazil. The discussion about the health crisis in the country gained momentum, mobilizing professionals, institutions, policies and the population. The implication of this debate went beyond the health field in its strictest sense, since it brought questions and proposals about the organization of life in society, including different actors in this construction³⁷. The re-democratization and the social conquests that followed, culminating in the promulgation of the Federal Constitution in 1988, changed the idea of social control, which came to be understood as popular participation in formulating, monitoring, and verifying public policies³⁸.

These social movements play a crucial role in the field of collective health. There are many and diverse social movements and this results from the historical process of citizenship maturation and construction of democracy as such; the country's diversity; and the interests of several actors. Moreover, these many social movements express different forms of struggle, according to the difficulties faced

by the actors for their social reproduction of life in the physical, political, and cultural environments in which they are immersed in³⁹. In fact, community leaders have a record of achievements regarding the improvement of living conditions in what structural weaknesses are considered⁴⁰. In this sense, health surveillance, mainly in actions of health analysis in the territory, was an important field in which the articulation between civil society and health services proved to be effective.

Originally, the approach of epidemiological surveillance in the Western world followed a military pattern of biological methods control based only on identification and mitigation, immunization, and development of therapies, without encouraging popular participation. Thus, despite information being vital for analyzing and monitoring the population's health conditions, health surveillance in Brazil is still organized in an authoritarian way, and this is due to the lack of the knowledge of civil responsibility and the difficulty in responding to new epidemics, such as the Covid-19 pandemic⁴¹. In opposition, participatory surveillance presents itself as a timely method to exhort the population to exercise their citizenship and support governments to identify localities⁴². This approach breaks away from the more traditional conception of epidemiology in favor of a more critical one vis-à-vis the complexity of the contemporary world.

From the origins of Epidemiology to a critical perspective

From the 17th century onwards, when the development of illnesses was still unclear and the perception of the human body was strongly associated with a work tool, emerged the interest in quantifying vital events, such as births and deaths for further analysis of the population's illness patterns, giving rise to the collective dimension of health⁴³.

With the emergence of microbiology in the 19th century, there was an inevitable confidence on the microorganism-human relationship as the main cause of disease occurrence. The monocausal model to explain the occurrence of diseases was supported by the outbreak of major infectious disease epidemics that prompted the adoption of specific strategies to deal with them. Several contagion control measures were adopted, including compulsory vaccination and social isolation. In this context, as a discipline, Epidemiology emerges and consolidates itself in an essentially biologicistic line, gaining prominence based on the pathology and the clinic. In that period, the development of research on communicable diseases motivated by economic interest and marked by the observation of phenomena stands out⁴⁴. Monocausality was based on the search for new etiologic agents, the discovery of disease transmission forms, and the proposition of therapeutic basis and prevention through vaccines⁴⁴. For the data analysis through quantification, methods and techniques were developed which gave rise to statistics; and, based on Cartesian analysis, comparison became predominant in the construction of health knowledge. The formalization of epidemiology as a field was then based on mathematics and logic, excluding other approaches to health analysis⁴⁵.

The economic expansion started in the 19th century and continued throughout the 20th century led to social reforms that resulted in a general improvement in the populations' living conditions, leading to an increase in life expectancy. The consequent aging of the population has changed the morbidity and mortality profile, marked by a decrease in the occurrence of infectious and parasitic diseases, and an increase in the occurrence of chronic-degenerative diseases. The new pattern of the population's illnesses caused significant changes in the models for studying disease causality, so as to encompass the complexity of the processes that have come to be established⁴⁶. As a result, from the 1970s and

1980s onwards, another trend in epidemiology emerged challenging its limits from a positivist and clinical standpoint, and including social variables as determinants of the health-disease process for a global understanding of health problems.

The studies of this new conception have induced the study of new approaches in public health and are often interested in investigating how social conditions influence and determine the health-disease process of populations, which has generated a growing articulation between epidemiology and the social sciences. This new trend is referred to by some scholars as social epidemiology⁴⁷. The advancement of this perspective has largely contributed to the construction of a bolder line of thought, which was key to the creation of critical epidemiology.

In Latin America, critical epidemiology gained ground from the discussion about social equity and the need to include other elements, besides those of classical biological basis, in epidemiological analyses. The development of a causality model centered on the social determinants of disease is presented as an attempt to overcome the theoretical-positivist framework of classical or conventional epidemiology⁴⁸. In opposition to classical epidemiology, which studies the distribution of diseases and their determinants in a population based on physical and biological characteristics, critical epidemiology has as its main focus the study of how society and the different modes of social organization influence the health and well-being of individuals and social groups, enabling the incorporation of their experiences for a better understanding of how, where, and why health inequalities occur⁴⁹. In order to assume this dimension in epidemiological research, attention to theories, concepts, and methods related to the social sciences is necessary, such as: biological expression of social inequality; discrimination; gender, sexism and sex; deprivation (material and social); life course; social exclusion; among others⁵⁰.

Broadening out this discussion, elements of anthropology are incorporated into critical epidemiology, which assumes that the same sign can have different meanings, depending on the individuals and their cultural context. In this sense, the boundaries between normal-pathological and health-illness would be established by the experiences of illness in different cultures⁵¹. Therefore, individuals with diseases and/or illnesses can often be identified as active individuals without limitations, while limitations and disabilities can be recognized in individuals without any kind of disease⁵².

Still on the relation between health and cultural aspects, the narrative of critical epidemiology is that health is not reduced to a mere adaptation to norms, but refers, above all, to the singular normative capacity. Thus, the perception of health implies openness to paradigmatic readjustments, setting up new norms, symbolic communication, and recognition of an intersubjective reality⁵³. Critical epidemiology is defined as an interdisciplinary and intercultural study of the processes that determine the production and distribution of collective health. It encompasses the set of social relations, ideas, and organized practices that human beings carry out, with strategic interests imposed by the political-economic system, according to their economic insertion, class affiliation, culture, and gender, as well as strategies in the individual domain. These processes must be studied together to unravel the socio-environmental roots of health problems⁵⁴.

Although the decline of infectious diseases, characteristic of the second half of the 20th century, has led to the study of the social determination of the health-disease process for the understanding of disease causality, the expectation generated by the infectious diseases eradication has not been realized⁵⁵. On the contrary, they have an increasingly unequal distribution among different individuals and social groups. A large number of factors are involved in determining the emergence and

reemergence of infectious diseases, which can be organized in multiple dimensions: demographic, social and political, economic, environmental, and health sector performance⁵⁶. Epidemiology, when considered in its social and critical dimensions, reveals itself as a generator of essential scientific knowledge for the production of data that enable a broad analysis of health and illness processes, considering individualities and the political, economic, and social contexts of a given society at a given historical moment. Then, there is the need to re-discuss the surveillance practice which no longer fits operational resources or coercive mechanisms of investigation and intervention protocols. It requires, above all, an alignment with popular practices and the induction of popular participation.

Admittedly, health surveillance has its history shaped culturally and epistemologically under the foundations of a universal scientific prerogative with the idea of social security and the imperative criterion of urgency. The prerogative of scientificity is based on the biomedical and clinical model that leads to a surveillance of 'cases'. The perspective of this model, conceived as hard science, does not allow critical and emancipatory conceptions that popular knowledge is a legitimate form of knowledge on health. The idea of social security, in turn, is based on the traditional health surveillance perspective, and presupposes that the State needs to impose social control, assuming a prescriptive attitude¹². The imperative criterion of urgency finally reveals a culture of the 'dictatorship of urgency'⁵⁷. In this case, health actions are used as instruments of domination over the community based on the justification of the urgent need for an effective intervention to protect it from the risk of epidemics and the disruption of the social order. Thus, a dominant relationship is established and the population takes distant from the legitimate popular participation in health policies and actions. Traditional terms derived from this conception of epidemiological surveillance, such as 'epidemiological

intelligence'⁵⁸, 'armed arm' of Epidemiology⁵⁹ and 'information for action', show the vertical relationship of 'health promoters' towards the population, seen as incapable of being the protagonist of its health production process and needing to be saved.

Civil surveillance and popular participation

The epistemological and cultural framework imposed by traditional health surveillance has been widely criticized by the so-called Epistemology of the South by Boaventura de Sousa Santos⁶⁰, which brings the conception that the dominant social sciences produced in the Northern Hemisphere, such as the biomedical model, have a highly regulatory character. Thus, the legitimacy of knowledge is limited to the knowledge and practices coming from the United States and Europe, and nothing beyond this perspective has scientific relevance. According to the author, the great social science theories produced in Northern countries do not fit our social realities. Moreover, very local experiences, not well known nor legitimized by the hegemonic social sciences, are harassed by the media, and, therefore, have remained invisible, discredited. In this sense, the author suggests the creation of 'rebellious subjectivities' as opposed to 'conformist action'⁶¹.

Paulo Freire's conception of popular education found echoes in Boaventura de Sousa Santos' discourse on the Epistemology of the South. The author strongly criticized the 'cultured norm science' and exalted popular knowledge as a scientific and emancipatory knowledge. This territorial dimension attributed to the surveillance actions was a favorable means for the emancipatory approach of the communities. This happens, above all, when the territorial dimension is understood from the perspective of Milton Santos⁶², in which the territory is understood as an existential space that transcends the physical

dimension, but a place where popular resistance and solidarity spaces are built and in which health surveillance should be carried out with community participation, consistent with the population's reality and from the dynamics of permanent knowledge exchange and technical-scientific and popular knowledge.

Regardless the advances brought about by the implementation of the SUS, the formal models of health surveillance continued to be questioned, as Porto⁶³ does when asking "to what extent we can think about surveillance in its emancipatory character, as well as its limits in current times?". The author made a counterpoint between the health surveillance in force in the Ministry of Health and in SUS, of operational character and based on the control of specific diseases, and an alternative proposal of health surveillance, based on the principles of collective health and sanitary reform, in order to consolidate the health sector as a promoter of strategic policies for social transformation and tackling social inequalities, intervening on the social determinants of health. In the end, this seems to be the way out for social transformation.

Final considerations

The concept of civil surveillance and its relations with non-institutional articulation strategies, absent from the normative texts of the Ministry of Health, reinforce the recurrent coercive practice of health surveillance in Brazil. Even after years of theoretical disputes about health concepts, including the incorporation of elements from the fields of social sciences, pure or applied, we still have an epidemiology practice that is not characterized by the contextual effects that explain the way of understanding health. Population studies, and demography in particular, have made valuable contributions in this regard. The scope of social epidemiology, as opposed to clinical epidemiology, and the perspective of critical epidemiology are reorienting practices

in the health field that deserve more and more emphasis.

The idea of 'Shared Knowledge Construction', coupled with civilian health surveillance, was a term coined in a collective way. The central idea of the concept is based on the assumption that 'subjects with different, but not hierarchical knowledge, relate to each other based on common interests' and can exercise positions of power to intervene in the processes that condition life. In this direction, the concept of civil health surveillance is largely influenced by the concept of community epidemiology, based on an active process of popular participation, from the diagnosis of the health situation, an instrument of community self-awareness.

The intersection of these aspects is strongly expressed in Victor Valla's idea of problematizing the local reality, promoting dialogue and listening, using multiple languages and methodologies to value the local reality with community empowerment. Ultimately, Valla's legacy is not only in the field of popular education per se, but to review the whole way of thinking about health practices that, in the limit, define the health care model in the country. Only in this way will it be possible to break with the current paradigm of surveillance, moving towards a monitoring of the social determination of health processes aimed at social transformation.

Collaborators

Guimarães RM (0000-0003-1225-6719)* has contributed to the conception, drafting and critical review of the final version. Martins TCF (0000-0002-6225-7245)* has contributed to writing, final revision of the manuscript, and approval of the submission version. Dutra VGP (0000-0001-6939-742X)* has contributed to writing, final review of the manuscript, and approval of the submission version. Oliveira MPRPB (0000-0003-2628-0023)* has contributed to writing, final review of the manuscript,

and approval of the submission version. Santos LPR (0000-0002-1225-3908)* has contributed to writing and final critical review of the manuscript. Crepaldi MM (0000-0002-5479-4016)* has contributed to writing a portion

of the manuscript submitted for evaluation. Cavalcante JR (0000-0003-2070-3822)* has contributed to writing, final review of the manuscript, and approval of the submission version. ■

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