



Revista Bioética
ISSN: 1983-8042
ISSN: 1983-8034
Conselho Federal de Medicina

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Ontologia política da doença: em defesa da saúde pública
Revista Bioética, vol. 27, no. 2, 2019, April-June, pp. 204-211
Conselho Federal de Medicina

DOI: <https://doi.org/10.1590/1983-80422019272302>

Available in: <https://www.redalyc.org/articulo.oa?id=361570647003>

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UPDATE

Policy ontology of the disease: in defence of public health

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Abstract

The debate about the role and scope of the Sistema Único de Saúde Brasileiro (Brazilian Unified Health System) has generated numerous stances and proposals for change, ranging from maintaining the current model, which is universal, to full privatization. This article aims to defend the universal and public health model, with reference to the works of the Italian sanitarian Giovanni Berlinguer. The basis of support for this proposal lies in the fact that health is a collective public good and, therefore, must be managed by this same collective, according to the particular needs. Through a re-reading of Berlinguer's works, a reference for the Brazilian model, the proposal advances in the discussion about the necessary public health and the connection of this with social stability. To consider such an influence in the context of social welfare means, at the same time, not segregating, not excluding and enabling all people to have a dignified life.

Keywords: Politics. Unified Health System. Disease.

Resumo

Ontologia política da doença: em defesa da saúde pública

O debate acerca do papel e da abrangência do Sistema Único de Saúde brasileiro tem gerado inúmeras posições e propostas de mudança, que vão desde a manutenção do atual modelo – universal – até a completa privatização. Este artigo visa defender o modelo universal e público de saúde, tendo como referência a obra do sanitariano italiano Giovanni Berlinguer. Esta proposta considera que a saúde é bem coletivo, público, e, portanto, deve ser gerida por esse mesmo coletivo, observadas as necessidades particulares. Baseada na releitura dos trabalhos de Berlinguer, referência para o modelo brasileiro, esta pesquisa avança na discussão sobre saúde pública e sua ligação com a estabilidade social. Considerar essa influência no contexto de bem-estar social significa, ao mesmo tempo, não segregar, não excluir e permitir que todas as pessoas tenham vida digna.

Palavras-chave: Política. Sistema Único de Saúde. Doença.

Resumen

Ontología política de la enfermedad: en defensa de la salud pública

El debate sobre el papel y el alcance del Sistema Único de Salud brasileño, ha generado innumerables posiciones y propuestas de cambio, que van desde el mantenimiento del actual modelo – universal – hasta la completa privatización. El artículo se inclina por la defensa del modelo universal y público de salud, teniendo como referencia la obra del sanitario italiano Giovanni Berlinguer. Esta propuesta considera que la salud es un bien colectivo, público y, por lo tanto, debe ser gestionada por ese mismo colectivo, observadas las necesidades particulares. Basada en la relectura de los trabajos de Berlinguer, referencia para el modelo brasileño, esta investigación avanza en la discusión sobre la salud pública y su conexión con la estabilidad social. Considerar esta influencia en el contexto de bienestar social significa, al mismo tiempo, no segregar, no excluir y posibilitar que todas las personas tengan una vida digna.

Palabras clave: Política. Sistema Único de Salud. Enfermedad.

Declararam não haver conflito de interesse.

Since 2017, Brazilian society has witnessed countless violations of social rights. There is no shortage of examples to describe how collective struggles and rights have been gradually replaced by subjective, oligarchic, monetary, and economic interests. The general population is apathetic towards politics and its lack of interest in fighting for its rights contradicts the true meaning of democracy.

It is often possible to witness the outbreak of a transformative movement that pushes away the empowerment of subaltern classes and uses the common agenda to promote only individual interests. Immediate consequences range from the economic penalization of society to the deliberate scrapping of the public machine, which “justifies” privatization¹. Healthcare is a social right guaranteed by the State, which is also one of the areas affected by the privatization process.

A process that results in the allotment of public goods and the outsourcing of government responsibilities, based on the decreasing withdrawal of society from political participation and the remunerated consent of the entrepreneurial class². The action proposal necessary to oppose movements that endanger universal healthcare requires adequate theoretical foundation that, in turn, enables – and justifies – transformative practices.

In order to reshape the present, it is necessary to understand the actions that took place in Brazil in the 1970s, especially those related to the Brazilian sanitary reform and the proposals of its patron, Giovanni Berlinguer, Italian Sanitarian. The idea is to demonstrate how the political ontology of disease affects society as a whole, that justify the maintenance of a public healthcare system and ensuring its quality standards. Hence, the proposal will point out situations and analyze contexts that prove how detrimental the interference of business practices in the Brazilian health system management model can be for the entire country.

Based on Berlinguer’s theoretical models, this article intends to demonstrate that healthcare is a public good that must be managed collectively. The implementation of a universal healthcare system that recognizes the social determinants of disease, avoiding its political ontology and emphasizing the dignity of life represents the best alternative for a more effective management model. It is clear that this text opposes healthcare privatization and outsourcing while proposing the retrieval of Brazilian history and the engagement of those committed to the sanitary movement and the construction of a healthcare

system that is universal and effective. In fact, it aims to ensure human dignity, which is extensively discussed by Berlinguer through his work.

Policy ontology of disease

In his book “A doença”, Giovanni Berlinguer starts off with the idea that *every element and every natural phenomenon, as well as every condition of human existence, can also become a source of illness*³. This reflection is based on the social determinants of disease: the author stresses that there is also inequality when it comes to disease.

Not that Berlinguer evokes the need for pathological equality. Based on the components of disease, it is possible to determine how its perception, evolution, and treatment will be – mostly because of sociopolitical issues and socioeconomic potential. The way a disease progresses in a particular country confirms that observation: in general, countries located in the southern hemisphere are unable to deal with disease the same way the northern countries do. Practically, the types of pathology seen across developed countries are different from those seen across underdeveloped and developing countries.

For Berlinguer⁴, disease is composed of three aspects, regardless of social or economic factors: 1) physical changes; 2) society and its overall knowledge of disease; and 3) its interpretation of different medical conditions. In addition, disease will always be defined and, consequently, it will entail a form of action/reaction/treatment built upon cultural and temporal realities.

Disease takes on a different role, definition, and mode of treatment depending on traditions and time. However, it is important to note that despite being preliminarily dangerous to human beings, pathology must be understood as a *vital phenomenon, a process, an action-reaction movement between aggression-defense, which is treated with a substantial health stimulus focused on the well-being and feeling good*⁵. Therefore, it is an integral part of the human and social developmental process, which cannot be ignored or neglected.

Berlinguer argues that health is a collective good. However, it presents individual characteristics, considering that each person relates to it differently. Despite its subjective aspects, disease relates to the whole society, including the consequences of neglecting a certain condition. It affects the entire

society, hence the need for collective solidarity towards a suffering patient⁴.

The dismantling of SUS (Unified Health System) to promote disease

The imposition of the neoliberal model has been influencing public policies and squandering social achievements. This reality does not exclude healthcare policies, neither the Brazilian health reform project, which started with the implementation of the Sistema Único de Saúde - SUS (Unified Health System). On the other hand, based on the new fiscal regime model – adopted by the Constitutional Amendment of 1995 –, the freezing of specific health expenditures corresponds to *the untying of expenses related to public health services and actions, (...) the reduction of public expenditure with healthcare per capita (...) [and] the increasing inequity among those able and those unable to access health goods and services*⁶. The same amendment pointed out that health expenditures, alongside social security, are the cause for the existing fiscal imbalance in Brazil, which led to the formation of a ministerial group with the participation of health insurance companies to create affordable health plans⁷.

Parallel to the dismantling of the State and, consequently, SUS, social issues also emerge as another relevant point amidst the political and economic scenario. The State deals with them as an attribution, since they are very sensitive to market conditions and impositions. The obligation – not that the State is truly concerned about social welfare – to satisfy financial interests, motivated mostly by the proposal for economic adjustment or reform, has created new problems and hindered the improvement of public healthcare. This scenario ends up contributing to more inequality.

There is no integration: *Social and health policies have lost their integrative dimension, both nationally and regionally, shifting towards a localist vision that specifies a certain area as the only space capable of providing answers supposedly more “efficient” and catering to the needs of the population (known today as “comunidade”)*⁸.

The localist movement, strengthened by the dismantling of SUS, states that families and people are responsible for their own health and well-being. The outsourcing of the State duty, coated with the false idea of empowerment, leads to situations that

can only promote disease, since, in most cases, the general population lacks the sanitary education required to deal with certain pathologies. This reality becomes even worse when it comes to the impoverished layer of the population, which relies solely and exclusively upon public assistance. Moreover, the State ends up exempting itself from the fundamental constitutional role of safeguarding the health and life of Brazilian citizens⁹.

In democratic countries, where people (in theory) are engaged representing the center of social structuring – where *res publica* takes on its true meaning, the State will act as a social institution in charge of popular organization. Therefore, the State will not oppose the democratic process. Likewise, citizens have been granted the right to participate in the political system and the approval process of any of its policies.

When reform is needed, in whatever context, popular participation is fundamental and mandatory. In the last few years, public interests have been pushed aside to foster economic subjectivities. The supposed crisis of the State justifies the reform based on ungovernability, if certain changes do not take place. The logic of the crisis is reversed: it is not State bankruptcy caused by private demands that leads to crisis; instead, it is the healthcare crisis, the bankruptcy of public care that really causes the State to experience critical mayhem. It is the welfare spending, and not the concessions granted to the debtors, that propels the reform.

Such theses are similar to those in force during 1970 in developed countries⁹. The solution proposed by the government, which completely disregards the needs of the people, must undergo *fiscal adjustment (this is not a fiscal reform in the broadest sense, which, by the way, has been “deferred” sine die); in addition to “market-oriented” economic reforms that are supposed to ensure “internal competition” and promote “international competitiveness” (!); a social security reform, which aims “to cancel privileges”, cutting off benefits and expenses; and a reform of the State apparatus aiming to increasing “governance”*¹⁰.

The final solution proposed by the system practically gives away the whole public management system to the private enterprise. This is the ultimate coup, camouflaged by the “economic freedom”, “market control” shield – acclaimed dynamics such as privatization and decentralization capable of supposedly optimizing the State. This entire movement ends up transferring the control of social goods onto private companies and organizations,

which hardly take into account the promotion of health; on the contrary, they will focus on profit before anything else.

By combining privatization with less investment destined to public health resources, especially after the approval of the Proposed Constitutional Amendment (PEC) 241, we return to the same health application capital rates seen in 2013, according to data provided by the Brazilian Center for Health Studies¹¹. The immediate consequence of such aberration is the scrapping of SUS, which directly affects needy and impoverished families, in addition to promoting diseases and aggravating very complex situations.

The dismantling of SUS promotes actions that, in fact, should be prevented. It is here that Berlinguer's ideas emerge in defense of public health. For the Italian professor, disease presents five processes that must be confronted and, at the same time, taken as reference action: 1) suffering; 2) diversity; 3) danger; 4) signs; and 5) stimulus.

Quite often, suffering results from causes allied to illness – it may derive from symptoms or be motivated by the loss of physical strength, motor skills, independence, and dignity. Such conditions become even more evident considering the fact that, in most cases, the healthy ones (prepotent) end up defining the future of the patient¹² (impotent and disempowered).

In order to minimize the suffering caused by disease, Berlinguer insists that the treatment must always fight the illness, and never the patient. He also emphasizes that being sick does not mean giving away social rights. On the contrary, the whole community must cater to the patient, since his/her treatment represents social assistance. But care must be offered cautiously – society must watch treatment closely and protect the patient against abuse, which would cause even more suffering. It is important that society is supportive without demonstrating compassion or mercy, but instead, commitment and common responsibility towards collective care.

The second process may seem strange, as Berlinguer himself stresses, but the idea of disease as diversity aims to translate several situations of normality and abnormality that define people's lives. These conditions can lead to social exclusion, especially in the case of certain diseases, such as leprosy and tuberculosis, including mental illness. In the past, there were episodes when questioning normality (or abnormality) meant being a carrier of disease, which lead to isolation. Often, this diversity

is judged by the bias of cultural and moral values, and its outcome is uncertain. The truth is that in such cases, illness would be the cause for exclusion, but it clearly becomes an instrument working on behalf of societal power relations¹².

Understanding health as diversity also helps to explain some of the selective barriers imposed upon public health programs, whose limitations are often justified by the State according to "scientific" background. In Brazil, the current dismantling of the State demonstrates how health can be affected: in order to obtain treatment, normality dictates that people must pay health insurance plans or call upon the judiciary to assert their rights.

The problem is that this type of action does not contribute to reduce pathogenic conditions, mostly because there is no investment in prevention and primary care. Disease does not contribute to the marginalization of people nor unemployment. Investing in health means empowering all areas of society – here focused on the role and interest of society to the detriment of the private sector, something that has not yet been fully understood.

Disease is never an isolated fact, with no consequences for the collective. It engages the whole society and brings more damage if it is not controlled. The danger becomes more evident when actions are not taken against disease, but against the patient instead. This phenomenon is not uncommon: in many cases, the patient is considered a "target individual" (a scapegoat, so to speak), excluded from society and considered as an isolated problem. It is understood that the effects of the disease will be minimized.

However, distress and difficulties resulting from dealing with disease and imposed upon the patient's family and social environment are neglected. Disease, although understood as such, cannot be treated as a specific responsibility attributed to one person or another, or even to an institution such as a hospital. This understanding changes the reality of the condition, which lies on the risks arising from dealing with the patient rather than looking closer at his/her critical condition.

From this situation arises the need for punitive medicine, for which being sick is to place ourselves as a burden or a problem for society, dealt with by medical practices. The diagnosis is put aside being replaced by the political judgment of the disease and the patient¹². To know how to interpret illness as a sign and to provide a solution are fundamental requirements for subsistence. This is because the intrinsic relationship among individual, disease and

society: the individual is to the disease what the disease is to society. Therefore, disease is a collective sign, whose path to change lies on epidemiology, prevention, and the participation of everyone involved in the health process¹². This is the only way to speak about the transformation of reality.

In sum, disease needs to promote solidarity among individuals, so that they prevent isolation, even if it is purposeful. It is necessary to bring individuals together, but never push them apart. The fight against disease must encourage equality, by equity, avoiding any differentiation. Instead, differentiation must incite debate on the patient's rights, as opposed to the paternalism inherent to many treatments. Disease must promote global attention to healthcare, including active patient participation as a way to turn life around.

Thus, it is necessary to start off with pathology to transform reality¹². The dismantling of SUS contributes to this situation instead of minimizing it, so it becomes urgent to protect public health as an indisputable necessity, rather than just a right. Neglecting healthcare will affect not only a particular social class or a particular country, but all of humanity.

The need for public health: Giovanni Berlinguer's apology

Giovanni Berlinguer was a scientist always concerned with social issues and committed to improving and protecting health as a universal right. For him, these issues should not be relegated to the domain of only a handful of individuals: health and, consequently, disease, are and must be collective concerns.

Based on this understanding, Berlinguer exposed the consequences of healthcare mismanagement and pointed out the need to treat specific determinants that can prevent other complicators, or existing ones from worsening. This process deals with fundamental aspects required for the maintenance of life, because, as Henry Sigerist states, quoted by Berlinguer, *in any society, the incidence of disease is largely determined by economic factors. (...) Poor quality of life; lack of food, clothing and fuel; poor housing conditions; and other poverty symptoms have always been the main causes of illness*¹³.

This observation is in line with the provision presented by the World Health Forum held in

1995, which, as Garrafa, Oselka and Diniz point out, indicated that *the main mortality factor and the leading cause of morbidity and suffering worldwide appeared almost at the end of the International Classification of Diseases (ICD), under code Z59.5 (...): extreme poverty*¹⁴. In many cases, this social condition points to serious situations in which the oppression and authoritarianism implemented by the State contribute to the emergence of pathologies.

The lack of basic survival and sanitarian conditions, combined with the inefficiency of the State, promote the emergence of diseases that can also lead to serious social consequences. On the other hand, several aspects are proposed which can become health promoters. Hence, health can only be spoken of in face of freedom and social prosperity – contexts controlled by economic dispositions nowadays.

Since social orientation is presented by the economic bias, which ends up segregating, excluding individuals and, consequently, preventing the generation of health and promoting disease, the struggle for change relies upon all the members of society who, troubled by the situation, denounce, at the apex of their political participation, the conditions that hinder the promotion of a dignified life and its cycle. *If medicine desires to achieve its goals, it must fully embrace political life and point out all the obstacles that hinder the normal completion of the life cycle*¹⁵. Hence the importance of being able to read the social determinants that promote disease in order to establish direct and forceful actions.

Berlinguer analyzes important aspects to identify the social determinants of disease, such as industrial and technological advances. In many cases, the false idea that development favors the quality of life hides practical potential consequences for the field of health, which in turn, become promoters of diseases. These include *excessive work hours; insufficient and inadequate food; the ferocious exploitation of women and children; unhealthy homes; and the lack of any form of education*¹⁵. Not to mention *poverty in its various manifestations; injustices; (...) bad nutrition; marginalization and social discrimination; insufficient protection of early childhood; discrimination against women; (...) urban deterioration; lack of potable water; widespread violence; gaps and disparity in social security systems*¹⁶.

Maintaining the conditions that contribute even more to the emergence of disease generates what Berlinguer¹⁷ calls “peaceful genocide”. The situation becomes worse due to the lack or inefficiency of supervision and the inertia of the

State. Changes will take place only when society starts to organize itself and demand improvements in working and living conditions. Achieving social benefits and the expansion of rights, in addition to gaining access to universal healthcare represent a significant improvement in the quality of life of the population, which is conducive to more dignity and higher self-esteem.

To complement the actions that oppose the social determinants of disease, Berlinguer argues that it is necessary to take care of the social determinants of health, especially *the protection and enrichment of common global assets such as water, the environment and knowledge, which are indivisible, irreplaceable, and not reproducible, in most cases*¹⁸. These are common, non-state goods that belong to the people.

Another important proposal is to transform health conditions according to eleven steps, namely: 1) *public participation and its influence on society*; 2) *economic and social security*; 3) *favorable conditions during childhood and adolescence*; 4) *healthy working life*; 5) *healthy and safe environment and products*; 6) *a health system that promotes good health*; 7) *effective protection against infectious diseases*; 8) *safe sex and reproductive health*; 9) *more physical exercise*; 10) *healthy eating habits and safe food*; 11) *less use of alcohol, tobacco, and drugs*¹⁹.

In addition, all the actions proposed by Berlinguer focus on a global dimension and consider health as a collective good. He points out that international cooperation is fundamental to overcoming injustice and inequality, in view of global good health as *an integral part of citizenship rights and (...)guaranteed as a "global public good"*²⁰.

Berlinguer's proposal for public health assumes that social medicine alone proves itself to be insufficient to analyze facts and take action. There is no way to separate health from politics, according to the Italian professor. So, any action aimed towards healthcare is political; doing politics is thinking about health. More than a simple practical consideration, health is a common process of interest that includes the whole society and, therefore, it is a collective issue.

To understand how collective health is directly connected to social, common issues, Berlinguer analyzes few central aspects of life in society and their consequences. With this reality in mind, he highlights a concept that has become essential for the Brazilian context: sanitary awareness, defined as *a person's right and a community interest. As this right is suppressed and the common interest ignored,*

*sanitary awareness represents the individual and the collective action required to achieve this goal*²¹.

By placing health as a right, the proposals for its maintenance lie upon the hands of the political representatives. There is no way to propose health without including politics. If it is necessary to discuss health as politics, and being the latter essentially dependent upon popular participation, health becomes object of social interest. Health-related actions (and lack of thereof) will affect all the individuals living in the community, that is, they will never be an isolated fact.

Sanitary awareness enables us to see social inequities and unhealthy human relations, mainly due to the contradictions between private for-profit healthcare and public health¹². This exposes the harmfulness of capital in regard to health and its maintenance, but, above all, it enables the disadvantaged classes to understand their situation and change their reality. Sanitary awareness also enables us to understand the role of social epidemiology and the health/disease process, which could assist the health reform, fundamental to change this scenario. This reform cannot happen unless cultural, institutional, professional, and administrative changes required to safeguard healthcare also take place.

In order to demonstrate his thesis, Berlinguer proposes the careful analysis of health in factories. There, where everything is more intense and violent, the real harmful agent is the capital, exploitation, and extreme working conditions²². The problematic reality seen in factories does not stay contained within their walls; it will contaminate the whole society, because external environment conditions also influence the health of workers. Thus, health is determined by both internal and external factors.

For Berlinguer, the reality will only change once the entire population decides to engage and understand that everyone is affected by the health-disease process. He supports the idea of sanitary reform, which is *not constituted only by procedural rules, decrees, and institutional changes. It must be a process that includes popular participation in the promotion of health, which involves millions of citizens; it must impose social, environmental, and behavioral changes that make life healthier; it must mobilize tens of thousands of regional, provincial, and state councilors, in addition to trade union representatives, women groups, cooperatives, youth, and thousands of advisers and mayors; it must change the daily routine of doctors, technicians, and nurses*²³.

The reformist movement will certainly change the social context and the reality of each individual. Although health presents itself as a private, individual fact, disease cannot be restricted in the same way. Disease requires redoubled attention, mainly because of its collective consequences. It also takes into account collective responses and actions, whether in the field of prevention, treatment, rehabilitation, or patient reintegration²². Health reform is a movement based on the common responsibility of social subjects.

Final considerations

Proposing collective health is, necessarily, addressing equity among people living in society. It is based on the logic of distributive justice and it is increasingly related to right to healthcare and human rights, whose promotion, despite the epistemological discussion that goes back to the ancient greeks, is fundamentally a matter of respect.

The Brazilian public health model, universal and egalitarian, seeks more than promoting health – it is how dignity of life is achieved and maintained. The proposal opposes the models that incite inequalities while catering to social stabilization through social welfare, ultimately seeking to defend life.

This means implementing and maintaining a model that considers health to be everyone's right and a collective interest. This dynamic translates what Berlinguer called sanitary conscience. Exactly for these reasons, health cannot be considered a

mere product that is negotiable, or that carries added value. Politicizing the issue based on the determinants of disease becomes the way to change social reality, because every disease brings collective consequences.

It is important to emphasize, as Berlinguer did in defense of the Italian health reform, that a proposal designed to address public health system issues does not mean full resolution of problems and difficulties. It is necessary to keep questioning and renewing the model adopted. This means that the existence and maintenance of SUS does not depend exclusively on government or public policies but is based on social participation in health promotion. It is important to constantly seek social, environmental, and cultural changes. Therefore, individualistic practices that contradict the collective essence of SUS cannot be represented here. In fact, the entire work struggles so that health overcomes disease, community overcomes individualism, politics overturns politicking, and humanism does not succumb to domination and exploitation.

In short, ensuring public health enables the maintenance of society itself. The dismantling of SUS, as a practice maliciously disguised to achieve market freedom and healthcare reform, violates precepts and the fundamental rights of citizens, threatening social stability. More than an apology based on the works of Giovanni Berlinguer, the intention is to stress that the lack of a universal health system will lead to the social bankruptcy of many Brazilian families. The consequences will not only be physical or personal, but diverse and unimaginable, since health (and disease) is related to all collective instances.

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Recebido: 9. 9.2018

Revisado: 27.11.2018

Aprovado: 10.12.2018