

Neglected diseases and bioethics: dialogue between an old problem and a new area of knowledge

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Abstract

Neglected diseases have long been the scourge of excluded populations, and are therefore of particular relevance to the field of bioethics. Neglected diseases are classified as a group of infectious diseases that are strongly associated with conditions of poverty, and are mostly found in peripheral countries. The aim of the present study was to bring together bioethical knowledge and existing knowledge of such diseases, demonstrating that, while they are different, such areas of knowledge can be used synergistically. A bibliographic review was performed with the aim of expanding knowledge of the following areas: 1) concepts and visions of neglected diseases and bioethics; 2) consequences and context of neglected diseases; 3) neglected diseases in bioethical studies. It was found that a dialogue between the two areas exists, and elements were identified confirming the value of bioethics as a mediation tool for overcoming the ethical conflict that permeates the issue of neglected diseases.

Keywords: Neglected diseases. Bioethics. Poverty. Social vulnerability.

Resumo

Doenças negligenciadas e bioética: diálogo de um velho problema com uma nova área do conhecimento

As doenças negligenciadas representam flagelo persistente no histórico das populações excluídas, sendo, portanto, objeto de interesse da bioética. São classificadas como grupo de doenças infecciosas fortemente associadas às condições de pobreza verificadas, em sua grande maioria, nos países periféricos. O objetivo deste estudo foi aproximar duas áreas do conhecimento por meio de diálogo, a fim de demonstrar que, apesar de específicas, ambas podem atuar de maneira sinérgica. Trata-se de estudo de revisão bibliográfica que procurou aprofundar o tema a partir dos seguintes eixos: 1) conceitos e visões das doenças negligenciadas e da bioética; 2) consequências e contexto das doenças negligenciadas; 3) doenças negligenciadas nos estudos de bioética. Verificou-se o estabelecimento do diálogo, bem como a emergência de elementos que ratificaram a bioética como campo de mediação a ser utilizado na superação do conflito ético que permeia o tema das doenças negligenciadas.

Palavras-chave: Doenças negligenciadas. Bioética. Pobreza. Vulnerabilidade social.

Resumem

Enfermedades desatendidas y bioética: diálogo de un viejo problema con una nueva área de conocimiento

Las enfermedades desatendidas se muestran como un flagelo persistente históricamente en las poblaciones excluidas, por lo tanto, son de un especial interés para la bioética. Se las clasifican como un grupo de enfermedades infecciosas que están fuertemente asociadas a las condiciones de pobreza verificadas, en su gran mayoría, en los países periféricos. Este estudio tuvo como objetivo aproximar dos áreas de conocimiento por medio de un diálogo abierto con el fin de demostrar que, a pesar de específicas, ellas pueden actuar de manera sinérgica. Se trata de un estudio de revisión bibliográfica que procura profundizar los siguientes ejes: 1) conceptos y visiones de las enfermedades desatendidas y la bioética; 2) consecuencias y contexto de las enfermedades desatendidas; 3) enfermedades desatendidas en los estudios de la bioética. Se verificó que hay un diálogo posible y también la necesidad de elementos que ratifican la bioética como un campo de mediación que debe ser utilizado para la superación del conflicto ético que permea el tema de las enfermedades desatendidas.

Palabras-clave: Enfermedades desatendidas. Bioética. Pobreza. Vulnerabilidad social.

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Declaram não haver conflito de interesse.

Humanity has long been afflicted by diseases associated to poverty which proliferate mainly in environments characterized by social exclusion. These are termed “neglected diseases” and, according to the World Health Organization (WHO) ¹, they comprise a set of 17 disorders that affect especially people living in the tropics, although they are not exclusive to these. This list includes such diseases as: trachoma; Buruli ulcer; African trypanosomiasis (sleeping sickness); Chagas disease (American trypanosomiasis); dengue; dracunculiasis; cysticercosis; leishmaniasis; leprosy; lymphatic filariasis; onchocerciasis; schistosomiasis; yaws; geo-helminths; hydrophobia (rabies); echinococcosis and fascioliasis. Data for the WHO ¹ on the issue reveal that many of these have been highly prevalent but, as societies developed and the conditions of life improved they gradually disappeared.

Faced with such evidence, it is required of bioethics to guide decision-making and practices developed by public and private sectors with the aim of confronting the problem, as expressed in the *Universal Declaration on Bioethics and Human Rights* (UDBHR) ². The promulgation of this document made explicit the duty of bioethics to bring the problem of neglected diseases to the center of the debate. This cannot be delayed, due to its socially relevant nature. In this sense, the critique of the bioethics that shares the space where the causes and effects of neglected diseases are concrete becomes crucial in the process of fostering political awareness intended to reverse this situation, contributing to the combat of the ailments that incessantly affect the health of individuals and their environment.

The path traveled by bioethics throughout its existence shows its consolidation as an autonomous discipline, continuously expanding its domain of action. From the start, the focus of its action was restricted to the health professional-patient relationship and to research involving human subjects. Along the years, from the need of a broader agenda, encompassing the relationship between health and society, especially the pressing issues in developing countries, its epistemological foundations were re-designed including, especially in the last decades, historically persistent issues related to poverty and social exclusion, such as neglected diseases.

The neglect that permeates the history of certain transmissible diseases associated with poverty directly impacts the social and economic conditions of marginalized populations living in the most part, the poor areas of low- and middle-income countries ³. Today, even with the pressing risk of contamination of at least 40% of the world population by a

neglected disease, it is noteworthy that they remain hidden in great part, concentrated in remote rural areas or in urban slums ^{3,4}.

For this reason, the line of bioethical thought advocated by the present article is that which centers its action in the resolution of ethical conflicts arising from iniquities and injustices and that usually stem from the asymmetries of power. For dealing with a theme that goes beyond borders, this paper seeks to not go beyond the references presented by those localities in which sanitary data show high rates of contamination or conditions greatly favorable to the development of neglected diseases, as is the case of Latin American countries ⁵. Other sources were accessed in the attempt to promote the unrestricted bioethical debate that could reach an international dimension.

Corroborating the perspective described above, Kottow ⁶ states that the bioethics developed by the peripheral countries needs to dialog with the hegemonic discourse, even the one coming from the outside; it cannot be disregarded under the risk of being stuck to lines of thought disconnected from the centers of decision and vulnerable to the conflict of interests that negatively affect the general well-being, mainly of socially vulnerable populations. So, the more conflicting and divergent bioethical systems with diverse moral origin become, the more important it is not to lose contact with the various discourse, including those practiced by the so-called central countries, holders of a dominant position in the world scientific production. Thus, the promotion of the dialogue with bioethics around a socially relevant problem with impact on global development is proposed.

Methods

The present paper consists in a review, based on specialized literature on neglected diseases and bioethics in order to check a possible dialogue between two topics in the field of health. The following data bases were used: SciELO, PubMed, Biblioteca Virtual em Saúde - BVS (“Virtue Library on Health”) and Google Scholar. For the search for scientific publications, the following criteria/descriptors were used: “doenças negligenciadas”, “doenças tropicais negligenciadas”, “prioridades de pesquisa” and “ética em pesquisa” (in Portuguese), and the corresponding terms: “neglected diseases”, “neglected tropical diseases”, “research priorities” and “research ethics” (in English).

Based on the survey performed on the sources, material relative to the scope of the study was selected. Articles, book chapters and documents relevant to the construction of the dialogue between neglected diseases and bioethics were selected. After reading and appreciation of the material, this article was prepared, from the definition of the concepts on the object posed to dialogue with bioethics, its consequences, the context of its emergence and its close relationship with the living conditions of the population. Then, the way in which theoretical studies of bioethics perceive and explicit the topic of neglected diseases was examined. The process of production of the present article was based on the exam of convergence points of a new area of knowledge and an old problem in the field of health that is permeated by an ethical conflict.

Bioethics and the collective look

Along its trajectory, bioethics has gone through reviews of both its conceptual definition and in the proposed actions. Concepts that had been left aside were revisited and reincorporated, this time with leading roles in the discourse of this discipline that, in essence, focuses on the survival of the human species. In this sense, it is noteworthy that, over thirty years ago, the U.S. physician Van Rensselaer Potter, when creating the new term *bioethics*, defined it as the area of science dedicated to the search of knowledge and wisdom. According to him, wisdom would represent the knowledge necessary to administrate knowledge itself with the aim of obtaining the social good⁷.

From his conception that understood bioethics as a bridge to the future, Potter proposed the improvement of science through ethics in order to ensure quality of life, transforming it in a discipline capable of following scientific development. Resting on ethical vigilance exempt from moral interests, and in the need to provide continuous democratization of knowledge⁷, bioethics has – from the time it was proposed by Potter to the present – searched to consolidate itself as an aggregating philosophical thought materialized through the contextualized plural dialogue focused on the mediation of conflicts of an ethical nature most of which affect with greater intensity the excluded or vulnerable share of our society⁸.

Although one may question Potter's proposition of bioethics as a science – since it focuses on values and deals with truths, not facts^{9,10} –, it is undeniable that, in the last thirty years, bioethics has

been the field of applied ethics that show the most progress. The analysis of its trajectory in the last decades shows three basic references that came to support a proposal of epistemological statute¹¹:

- 1) A structure with an approach necessarily grounded on multi-inter-trans-disciplinarity among several nuclei of knowledge and different perspectives of the questions observed, from the interpretation of the complexity: a) of technological and scientific knowledge; b) of the knowledge socially accumulated; c) of the concrete reality in focus, of which we are a part;
- 2) Respect to the moral pluralism present in secular postmodern democracies, guided by the search for balance and observation of specific social references that guide people, societies and nations to the sense of tolerance without imposition of moral patterns;
- 3) The understanding of the impossibility of universal bioethical paradigms, leading to the construction of a new bioethical discourse supported by dialogue, coherence and argumentation.

From this new way of thinking bioethics, issues long persisting in the history of mankind came to a prominent place in the proposals prior to the agenda for the discipline in the XXIst century¹²⁻¹⁴. It should be noted that, as a pioneer, Berlinguer¹⁵ had adopted the terms *everyday bioethics* to describe issues concerning to situations that happen every day, but should not happen anymore, like poverty, social exclusion, and neglected diseases. In Brazil, Garrafa and Porto used the same definition, adapting the idea for *the bioethics of persisting situations*¹⁶.

What matters is that both the proposition by Berlinguer¹⁵ and the one by Garrafa and Porto¹⁶ stress the need to think bioethics and capable of approaching the basic social determinants of – and, thus, persistent and critical to – human life, both individually and collectively. The encounter of bioethics and the collective, with the social, appeared timidly from the mid 1990s and grew strong in the following having, as protagonists, authors from Latin America seeking a bioethics focused in the issues of social inequalities and equity, social justice, individual and collective responsibility on healthcare, allocation and prioritization of scarce resources, poverty, racism, public health and social and sanitary policies^{11-14,16,17}.

It should be noted that bioethics, as a new way of valuing life, must establish a strong relationship with social issues that directly impact the health status of populations, especially the poorer

ones, present both in peripheral as in developed countries. It cannot be limited to strictly biomedical issues. Questions of justice, solidarity, humanity and equity must be protagonists in the analysis of bio-ethical conflicts, since these conflicts are the means by which the access to welfare and the right to a more dignified life may become realities¹⁸.

Neglected diseases and bioethics

The brief introduction on bioethics and its link to issues of social relevance that persist in the history of human populations reveals the logic adopted in this article, that is, to stimulate the dialogue among neglected diseases and bioethics, even facing the specificity of each area of knowledge. In our view, three fundamental facts act as key elements in establishing the dialogue between the two themes.

The first of these is the persistence that neglected diseases show in the health framework, no longer restricted to the local, but to the global context¹⁹, as mentioned above. The second fact is that bioethics and neglected diseases, even considering the specificity of each, follow convergent paths in some aspects. In the history of both, one can see issues related to social determinants and to health contexts, making them complex transdisciplinary areas of knowledge that need to be analyzed in their whole²⁰.

Based on the thoughts of Sotolongo²¹, we may confirm that both the themes of bioethics and those of neglected diseases have to deal, in their practices and theoretical reflections, with circumstances, situations and phenomena relative to life and sustainability, emanating from interactions among humans, mainly social interactions. Some of these interactions affect others, producing unexpected and paradoxical circumstances or phenomena for which there is not always a solution predicted or thought, setting the complex character of the two thematic areas.

It may be said that they are transdisciplinary because they are fields of knowledge that reach beyond the delimiting borders of the subjects involved in the study of their objects, in the dialogues that lead to new knowledge as well as to the reciprocal of all the agents in which the whole is more than the parts²². Transdisciplinarity promotes the overcoming of the barriers that mark the limits in the several disciplines, in promoting the continuous exercise of exchange which is expressed in distinguishing, not sectioning; associating and interlinking, and not reducing or isolating; making complex, and not

simplifying²³. Both areas are complex because they deal with themes involving context and surroundings sensitive causality, concerning natural, social and human components. It is a causal relation both sensitive to what is happening now and to history or the past of these components²¹.

It must be noted that the complexity allows for the distinction of properties emerging from the interaction among the parts and their relations with the whole, projecting themselves beyond the classic deterministic model as it captures, from this point on, the notion of disorder, unpredictability, error and chaos as fostering evolution and change²⁴. For Morin²⁵, facing the complexity of reality means to confront the paradoxes of order/disorder, of part/whole, of singular/general; to incorporate chance and particular and components of scientific analysis, integrating the singular and evolutionary nature of the world to its accidental and factual nature.

According to Garrafa²⁴, all conceptual elements previously presented may be worked according to adequate criteria, contributing to the construction of a new bioethical thought, broad and committed to the persisting ethical questions, most of which can be found in the reality of peripheral countries. As a consequence of this finding, the third and last determining fact for the dialogue established in this article. Complexity and transdisciplinarity of the two areas encourage bioethics to adopt a more critical and politicized posture on the ethical questions involving social determinants of health in social contexts that, in general, include excluded populations with high degree of social vulnerability, as is the case of those where there are neglected diseases and neglected diseased people.

Considering what has been exposed thus far, it is possible to say that, in the present stage of mankind, tolerance to the consequences of neglected diseases has become unacceptable. The paradox is explicit. With the advances of genetic engineering there is treatment to previously untreatable diseases, but right next door there are people living in subhuman conditions, fully predisposed to diseases that should no longer occur.

As indicated, the preferential *loci* for neglected diseases is the context left behind by the social economic development; consequently, these are contexts that live outside the scientific and technological development reached by humanity in the last years. It is observed that the relationship established between misery and neglected diseases has increased the problem of poverty of several populations around the planet. Thus, one can consider

poverty, simultaneously, as the starting point and final result of neglected diseases²⁶. For Pogge²⁷ and Luna²⁸, poverty must be seen as a violation of human rights, mainly when caused by many in the rich or central countries in their perverse action on poor or peripheral countries.

The common denominator of poor and excluded individuals is helplessness, a condition in which one needs protection and also the means to obtain it, in a way to avoid the progressive worsening or chronicity of exclusion and poverty that tend to occur in the lack of external aid. The negative synergy between disease and poverty requires protection that must be available and accessible as protecting function by the State, establishing itself as a moral right that extends beyond, according to the prevailing political doctrine⁶.

In our view, the bioethical conflict linked to the theme of neglected diseases, besides being relevant, becomes a concrete fact in face of its magnitude. This is confirmed when one finds that neglected diseases, besides afflicting 80% of the population of peripheral countries, also cause millions of deaths per year. It is estimated that in order to combat this evil that perpetuates itself in the history of mankind, it is necessary count with therapeutic resources corresponding to 20% of the production of the world pharmaceutical market²⁹.

However, when one deals with actions focusing the combat of neglected diseases by the world pharmaceutical industry, what one sees is that this industry usually destines most of its therapeutic resources to the demands of the market, leaving in second place the needs of thousands of people excluded or afflicted by diseases present only in the sanitary reality of peripheral countries³⁰. A study about the research focusing neglected diseases involving the main pharmaceutical industries in the world found that only 1% of the yearly budget of some of these was destined to finance studies that contemplate these diseases³¹.

Corroborating the situation described above, of the thousands of new drugs launched in the last 25 years, we find that a very low percentage (below 1%) was destined to treating diseases related to poverty²⁹. That is, the data presented demonstrate and confirm that neglected diseases do not represent an attractive market for the pharmaceutical industry, mainly because their target market usually does not have the resources to afford these drugs³².

It is noteworthy that in the period between 1975 and 2004, 1556 new drugs were developed, of

which only 21 were destined to neglected diseases³³. Besides, between 2000 and 2005, none of the twenty pharmaceutical companies with the largest gross sales launched a single drug to diseases related to poverty, that afflict in the largest scale the populations of peripheral countries³⁴.

Such fact is confirmed when Franco-Paredes and Santos-Apreciado²⁶ warrant that many socially excluded individuals, having few options and rare opportunities to avoid disease do not receive treatment to avoid incapacitation and premature deaths caused by poverty-related diseases. Thus, based on these needs, the State as promoting agent for social welfare, along with the organized society, must intervene in the attempt to eliminate these differences, or reduce them to the minimum possible. These inequalities, despite unnecessary, avoidable and unfair³⁵, are evident in the history of poor and outcast populations.

Schramm³⁶ also states that extreme poverty turns people into hostages, victims whose fundamental liberties were sequestered, keeping them from fulfilling their projects in life, since they are forced to live in conditions that deprive them of the competence to reach an objectively and subjectively dignified. Such individuals and populations may be considered affected, made vulnerable³⁷ and excluded by the process of globalization in course, fitting in the basic characteristics of those likely to develop some type of neglected disease. This way, it is possible to think bioethics as a practice capable not only to expose and debate moral in the intention to protect individuals and populations against threats that may irreversibly harm their existences, but also to recommend strategies to face inequities.

Besides, bioethics must reinforce through its discourse, that health care cannot be compared to a good to be bought and sold in any way in the market^{35,38}. To the extent that these facts tend to happen, we move toward exclusion, separation and isolation of those population groups that were deprived of the benefits provided by progress³⁹.

According to Farmer and Campos⁴⁰, the advances of science in the field of health take place in dissimilar ways, according to each social context, making the fruits of these advances to the ones who need them the most. Also, according to these authors both the right to health and the right to participation in the advances of science are explicitly different when we compare central and peripheral countries. In the view of Garrafa⁴¹, it is indispensable that a new bioethics, more dynamic and more politicized, build and make available to the locali-

ties most in need of the minimum goods for human survival, a set of concrete tools originated from scientific theory and the scientific method, which make possible the due dignity that has been denied so many times to so many. In this sense, universal access to health becomes an obligatory item in the new bioethical agenda of the XXIst century, seen as a right, citizenship, the State must provide the minimum necessary for people to live in dignity.

To the eyes of the world, neglected diseases keep leaving their mark and making more and more victims through disfigurement, stigma, incapacitation, and premature death²⁵. The more susceptible groups, both in frequency and in magnitude of the lesions are invariably the ones in social economic disadvantage⁴². It is enough to note that, due to diseases such as onchocerciasis and trachoma, individuals develop blindness; that leprosy and lymphatic filariasis makes them deformed, limiting their social life and their productivity. Deformities and amputations still happen as a means to prevent the deaths of individuals affected by Buruli ulcer; human African trypanosomiasis (sleeping sickness) severely weakens before leading to death; rabies, which causes acute encephalitis, is always fatal; leishmaniasis leaves deep and permanent scars or totally destroys the mucous membranes of the nose, mouth and throat, and in its most severe form, attacks the internal organs, leading to rapid death if not treated in time; Chagas disease can cause heart problems in young adults, occupying hospital beds instead of jobs in the labor market; severe schistosomiasis prevents school attendance, it contributes to malnutrition and impairs cognitive development of children⁴³.

In other words, the body, as a mirror to the scourge of neglected diseases, must be recognized as the parameter of ethical intervention not limited to the physiological dimension. It is in the body that the social dimension is identified and incorporated, that is, the articulation of the physical and psychical dimensions that manifest in an integrated way both in the social relations and in the relations with the medium. In considering the physical body as the structure to support social life, for without it, there is no social life, the concept of corporeality and the consequent maintenance of the concrete existence of people become benchmarks of the ethical intervention⁴⁴.

Innumerable marks that show in the bodies and in the lives of individuals become clear examples of the degree to which certain individuals and populations were subjected to neglect. Another fact that calls attention and must be brought to the

debate is the impossibility to dissociate the biological dimension of the disease and the social context surrounding it since, in most cases, both occur concurrently. For Porto and Garrafa⁴⁵, social players produce and reproduce the dynamics of the society in their bodies and in their lives, which reinforces the proposition of this article.

The understanding of human beings as simultaneously biological, social, cultural, and symbolic beings becomes more concrete from a broad approach to disease. The conditions of life of individuals and of the population determine their health conditions which, in turn must be studied in a broad perspective, taking into consideration not only biological elements but also social, cultural and symbolic elements^{46,47}. In this sense, we see that bioethics – as a transdisciplinary and complex area of knowledge linked to questions related to life, health, and the environment – has the ability to provide clear and transparent analyses, revealing the assumptions that drive the knowledge and the practices in health. Through its mediation and its ethical debate, we intend to promote the ethics of knowledge which, in the case of neglected diseases, becomes a key to reverse their condition.

Presently, in the discussion on transplants, implants, the Genome Project that prolong life, it is necessary to be attentive also to the persistent need to find solutions for the diseases related to poverty, such as malaria, dengue, leprosy and many others that still reap lives early in much of the world, and that remain epidemic for the most vulnerable and poorest populations⁴⁸.

For this, bioethics must stimulate the dialogue with these problems from the principles of justice, equity, and solidarity, considering the need of sensitization for the suffering of others, so that resources can be shared in legitimate ways, emphasizing the need to provide less unequal conditions; only so it is possible to promote the access to good and services without which it is impossible to foresee a more fair future⁴⁸. Critically understanding reality we can interpret the past and project a future of dignity to all²⁰.

Final considerations

In face of the facts presented here, it is possible to see that the bioethical conflict that surrounds and goes into the theme of neglected diseases is set and claims for its solution. This corroborates the fact that, being applied ethics, focusing on issues related to life, bioethics must be used as an instrument

of mediation with the power to drive to process of reversal of the condition present in the history of many transmissible diseases directly related to the conditions of life present mainly in populations of peripheral countries.

We believe that the dialogue between neglected diseases and bioethics is based on both the references of bioethics itself, which are meant to expose the real problems of persistent inequalities in the contemporary world, and by references that propose to carry out health as a fundamental right of the human being, bringing to practice the definition proposed in Article 14 of the *Universal Declaration on Bioethics and Human Rights* by UNESCO².

This article of the UDBHR, besides defining that the promotion of health and social development must be the central object of any democratic government, considers that enjoying the highest standard of health constitutes one of the fundamental rights of human beings and that, for this, access to quality health care and to essential medical drugs must be warranted to all people, especially the care and drugs for treatment and maintenance of the health of women and children, as health is essential to life itself and must be considered a human social good².

Finally, it appears that the bases of the reflections and discourses used by the authors in the construction of the present article rest largely on the bioethical discourse intended to overcome the social and health inequities and asymmetries established between those in power and those without any power who, for the most part, live under persistent situations that still affect humanity.

In this sense, it is found that the views brought to this article, in general developed by authors that reject the insensitive and indifferent mode of treatment dedicated by many to a problem with an impact that reflects on the lives of millions of people, are guided by the commitment to the construction of a participatory and politically engaged bioethics, in order to overcome the undesirable and persistent problems present in the peripheral countries.

Therefore, the role of bioethics in overcoming the heavy burden caused by the scourge of neglected diseases, in addition to amplifying, through its speech, the voices of those who have no visibility, must be to reject the possible causes that deprive individuals - especially those who are in a socially vulnerable condition - of access to quality health care and to medicines that are essential to their survival.

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