Revista Latinoamericana de Bioética
2024
julio-diciembre
Vol. 24(2)
ISSN: 1657-4702 · e-ISSN: 2462-859X ▪ pp. 27-38
Editorial Neogranadina
DOI: https://doi.org/10.18359/rlbi.6433

Decolonial Critical Bioethics and Access to Treatment for Hemophilia in the Americas*

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Abstract: Over the past two decades, the integration of sociology with the analytical and normative practices of bioethics has become firmly established. This integration has given rise to two similar yet distinct conceptions of bioethics: empirical bioethics, which utilizes social sciences to enhance ethical scrutiny, and critical bioethics, which not only employs research methods but also draws from established social theories. Critical bioethics aims to overcome the decontextualized analyses inherent in the concept of applied ethics, which relies solely on moral philosophy. This epistemic deepening enables a comprehensible evaluation of the impacts of biotechnologies' production and distribution within their social and global contexts, ultimately leading to more robust normative frameworks. This article presents the conceptual framework of a model of critical bioethics that we term "decolonial", developed through the synthesis of the Frankfurt School and decolonial studies. To illustrate the relevance of its analytical parameters, we will examine to clotting factor concentrates in countries across the Americas.

Keywords: Bioethics; Hemophilia; Health Services Accessibility; Health Care Ethic; Social Inequity

Recibido: 27/08/2022 **Aceptado:** 24/05/2024 **Disponible en línea:** 24/10/2024

Cómo citar: Lorenzo, C., Cunha, T., Sayago, M., & Sarmet, M. (2024). Bioética crítica decolonial y acceso al tratamiento de la hemofilia en las Américas. *Revista Latinoamericana De Bioética, 24*(2), 27–38. https://doi.org/10.18359/rlbi.6433

* Research article

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Bioética crítica decolonial y acceso al tratamiento de la hemofilia en las Américas

Resumen: En las últimas dos décadas se ha consolidado la integración de la sociología con las prácticas analíticas y normativas de la bioética. Esta integración ha dado lugar a dos concepciones similares pero distintas de la bioética: la bioética empírica, que busca únicamente el uso de las ciencias sociales para reforzar el escrutinio ético, y la bioética crítica, que propone, además del uso de métodos de investigación, una fundamentación en teorías sociales consolidadas, que busca superar los análisis descontextualizados inherentes al concepto de ética aplicada, basado únicamente en la filosofía moral. Esta profundización epistémica permitiría evaluar los impactos de la producción y distribución de las biotecnologías en su dimensión social y global, favoreciendo una mejor elaboración normativa. Este artículo presenta el marco teórico conceptual del modelo de bioética crítica, que llamamos "decolonial", construido a partir de la articulación entre la teoría crítica de la Escuela de Frankfurt y los "estudios decoloniales". Para demostrar la relevancia de sus parámetros analíticos, examinaremos el panorama del acceso al concentrado de factor de coagulación en los países de las Américas.

Palabras clave: bioética; hemofilia; accesibilidad a los servicios de salud; ética asistencial; inequidad social

Bioética crítica decolonial e acesso ao tratamento da hemofilia na América

Resumo: Nas últimas duas décadas, a integração da sociologia com as práticas analíticas e normativas da bioética tem se consolidado. Esta integração resultou em duas concepções semelhantes, mas distintas, de bioética: a bioética empírica, que busca unicamente o uso das ciências sociais para reforçar o escrutínio ético, e a bioética crítica, que propõe, além do uso de métodos de pesquisa, uma fundamentação em teorias sociais consolidadas, que busca superar as análises descontextualizadas inerentes ao conceito de ética aplicada, baseado unicamente na filosofia moral. Este aprofundamento epistemológico permitiria avaliar os impactos da produção e distribuição das biotecnologias em sua dimensão social e global, favorecendo uma melhor elaboração normativa. Este artigo apresenta o marco teórico conceitual do modelo de bioética crítica, que chamamos "decolonial", construído a partir da articulação entre a teoria crítica da Escola de Frankfurt e os "estudos decoloniais". Para demonstrar a relevância de seus parâmetros analíticos, examinaremos o panorama do acesso ao concentrado de fator de coagulação nos países das Américas.

Palavras-chave: bioética; hemofilia; acessibilidade aos Serviços de Saúde, ética assistencial, inequidade social

Introduction

In the last decade of the twentieth century and the early years of this century, sociological studies identified significant limitations in the theoretical models of conflict analysis and normative deliberation within bioethics. Among these limitations were the inadequacy of the "applied ethics" model to examine the influence of socioeconomic and cultural contexts on the generation and potentialization of conflicts (1) the failure of deliberative models to accommodate moral plurality and cultural diversity (2) and the observation that the strength of ethical claims often outweighed their cognitive foundations and theoretical assumptions (3).

In response to such criticisms, the integration of sociology and bioethics evolve significantly. By the end of the first decade of this century, sociology was firmly embedded in the theoretical frameworks and the analytical and normative practices of bioethics De Vries, Scott and Kim (4). This integration resulted in two main approaches within bioethics. The first, termed "empirical bioethics", aims to extend beyond social science research methods to understand the contexts surrounding conflicts or the perspectives of those involved (5).

The second approach, known as "critical bioethics", aims to extend beyond social sciences methods by incorporating deeper epistemic integration at the theoretical level, seeking to transform bioethical rationality, which had previously been grounded solely in moral philosophy (1, 6-9).

However, critical bioethics has diverse perspectives regarding the scope of its field. Some scholars focus on bioethics from a more restricted biomedical perspective, concentrating on the impact of new biotechnologies on individuals (1,6). Others critique this limited view and advocate for expanding the field to address conflicts related to environmental issues and global public health, (9), as well as incorporating counter-hegemonic social theories such as feminism and anti-colonialism (8).

(8) proposes a model of decolonial critical bioethics, which is a theoretical model based on the articulation of two social theories: the critical theory of the Frankfurt School and decolonial studies (9-12). This model is particularly suited for analyzing ethical conflicts in public health and global issues related to the production, distribution, and access to biotechnologies.

Among the various global public health issues related to biotechnology, rare diseases, particularly hemophilia, are of significant concern. The most recent report from the World Federation of Hemophilia (WFH) indicates that over 210.000 people worldwide have hemophilia. In the Americas, 21% of these individuals reside, with the United States and Brazil being among the top four countries affected (13).

Long-term regular replacement therapy with clotting factor concentrates has been shown to be the most effective preventive measure for increasing patient survival and preventing frequent joint bleeding and its disabling arthropathic consequences (14). However, the chronic nature of the illness necessitates substantial care infrastructures (15) with clotting factor concentrates accounting for more than 90% of the total treatment costs (14).

A major barrier to global access to prophylactic treatment is the limited number of industries capable of producing the plasmatic or recombinant clotting factors. Additionally, the commercialization of these treatments operates under free market principles, which often result in high prices (16).

This article aims to present the theoretical framework of decolonial critical bioethics and demonstrate the relevance of its analytical parameters by examining the disparity in access to hemophilia treatment in the Americas.

The construction of a decolonial critical bioethics

The term "critical bioethics" first appeared in the literature in an article by Parker (1). In this work, Parker examined genetic screening protocols for breast cancer and used contemporary science philosophy to critique conventional bioethics. Parker highlighted how traditional bioethics often neglected contextual factors and diverse worldviews in ethical conflicts. At the time, she also established reflexivity as a core principle of critical bioethics,

emphasizing the need for ongoing self-examination of normative commitments (1).

Nine years later, Hedgecoe (2) expanded on this concept by challenging the reasoning methods of "applied ethics". He criticized the tendency to treat sociocultural factors as mere epiphenomena, irrelevant to the application of supposedly universal ethical principles. According to Hedgecoe (6) this reductionist approach undermined the validity of bioethics claims in debates over new technologies and their practical impact on decision-making. Citing DeVries and Conrad (3) he pointed to the American bioethics community's neglect of issues like health financing and access to health services, noting that around 40 million Americans lacked health coverage.

Building on this critique, Hedgecoe (6) advocated for a deeper integration of bioethics with social sciences. He argued not only for the use of empirical methods from these sciences to inform ethical reasoning, but also for a more profound epistemological integration, capable of transforming the very characteristics of rationality of bioethics and surpassing the model of "applied ethics."

The author outlined four inherent characteristics of critical bioethics: 1. **Empirical grounding** through the use of methods from the social sciences; 2. **Theory challenging nature**, particularly concerning the interaction between social sciences theories and bioethical deliberative models; 3. **Reflexivity**, as defined by (1); and 4. **Politely skepticism**, proposing a stance of refusing to enter into disputes over different perspectives, while remaining sensitive to the complexity of justifying truths involving ethical issues in the field of health.

Hedgecoe (6) started from the notion of bioethics that has been considered, particularly prevalent among European and Latin American scholars. This view largely confines bioethics to biomedical ethics, diverging from the broader vision of the discipline's founder, Potter (Potter, 1971), envisioned bioethics as encompassing environmental issues, global health, equitable access to scientific benefits, and the survival of humanity and nature.

Twine (7) supported the interdisciplinary and reflective nature of critical bioethics, echoing Hedgecoe (6) but criticized this author for adopting a reductionist approach. On this subject, Twine (7) remarked, "The contemporary narrowing of bioethics to a primary concern with the application of philosophical principles to medical ethics appears as both a confusing and unfortunate act of enclosure" (Twine (7) 287).

Ultimately, Twine (7) argued that critical bioethics requires expanding the "bio" component beyond the anthropocentric and ethnocentric constraints of convectional biomedical ethics. This reductionist perspective characteristic that drove conventional bioethics to remain in its uncritical analyses supported in theoretical categories like universalism and rationalism, inapplicable to people's diversity and to environmental and global health problems.

Twine (7) highlighted the importance of critical bioethics by addressing the internal debates produced by theoretical perspectives that appeared in the specific field of bioethics, such as theories of feminist origin Rawlinson (19) and the perspectives that denounced and opposed what they called neocolonialism in Western ethics (20).

More recently, Árnason (8) critically examined the constitutive elements of critical bioethics, according to the proposal by Hedgecoe Hedgecoe (6) proposing additional contents that he considered indispensable for its theoretical solidification. He began by recognizing that conventional bioethics, strictly based on moral philosophy, was given to three main types of errors: prematurity in critical analyses, an uncritical understanding of its own theoretical assumptions, and restrictive framing of bioethical issues.

Similar to Twine (7) Árnason (8) also challenged the narrow understanding of the bioethics field developed by Hedgecoe (6) (Hedgecoe, 2004), which focused solely on the critical assessment of biotechnologies with regard to their effects on individuals. For Ármason (8) empirical grounding was merely contribution of the social sciences to bioethics. Equally important was the foundation in well-established social theories, which enabled a "sociological imagination" (Árnason 2015, 162) to address ethical conflicts. This perspective allowed for the application of hermeneutics to understand the influences of ideologies and power relations in

discourses on biotechnology. Arnasón also emphasized the importance of public spaces where normative deliberations are formulated and defended the need for dialogical practices grounded in communicative rationality, as referenced by Habermas (21).

For Árnason (8) one role of critical bioethics is to address the erosion of political and normative spaces concerning issues that threaten contemporary societies. It established four essential characteristics for critical bioethics to fulfill this role: 1. understanding the socio-cultural context of argument formulation and engaging with various positions on a specific ethical issue; 2. Maintaining critical awareness of the theoretical assumptions guiding analysis; 3. evaluating the broader social and global implications of biotechnologies in a reasoned manner; and 4. ensuring normative deliberations supported by free dialogical practices, communicative rationality, and attentiveness to power relations that might suppress arguments against hegemonic positions.

In Latin America and other peripheral regions, public health issues, particularly social vulnerability and inequalities in access to both new and established health technologies, remain central to bioethical concerns. In response, the region has developed theoretical models of counter-hegemonic bioethics (22) that reflect a geopolitically localized understanding of how contextual conditions, such as social vulnerability, impact access to technologies and other health goods (23).

A model of critical bioethics aligned with the perspectives of Twine (Twine (7) and (Árnason, 2015) has emerged in the region. This model integrates theoretical assumptions and analytical categories from the Frankfurt School's critical theory with decolonial studies, aiming to develop analyses, reflections, and normative propositions from a perspective specific to peripheral countries (9, 24-26).

In this model, the epistemic structure of critical bioethics consists of two components: an analytical component, which investigates the context, power dynamics, ideologies, and interests involved in a specific ethical conflict related to biotechnologies, and a prescriptive component, which proposes normative deliberations.

For example, in the analytical component, categories were derived from the seminal work of Horkheimer, who established the critical theory of the Frankfurt School in the early 1930s (27). Horkheimer critiqued the traditional theory of science, inspired by Descartes and Newton, which portrayed scientist as neutral observers of the phenomena they studied. This traditional view excluded reflections and evaluations of the social consequences of scientific research.

In other words, science was initially guided by a traditional theory motivated by an ideology of domination over nature and other people. Based on this conclusion, Horkheimer proposed that critical theory should developed a science that transcends the dichotomy between factual truth and value- based truth.

Scientific investigation, whether of natural or socio-cultural phenomena, should be driven by values and interests related to the emancipation of human groups subjected to various forms of historical exclusion. These ideas would later align with the functions of science as conceived by the pioneering bioethics, Potter (18).

Other key aspect of the critical theory foundation to this model was Marcuse's concept of the scientific-technological-industrial complex, (28) 1991). This concept is crucial for understanding both the current model of production and distribution of biotechnologies, and the uncritical stance of conventional bioethics.

Marcuse (28) demonstrated how the combination of traditional science, detached from moral considerations, and the instrumental rationality of economic and political powers led to the formation of an industrial scientific-technological complex. This system was closely linked to capitalist market interests, focusing on generating products primarily for commercial purposes, often disregarding their potential impacts on human health and the environment.

The emergence of this complex was fundamental to the development of modern industrial societies, where technologies began to exert a kind of fetishistic influence on citizens, a phenomenon that was then absorbed and normalized by the mass media. This process ultimately led citizens

to adopt a conformist attitude toward their professional and civil practices and to engage uncritical consumption of technologies. Marcuse described such citizen as a "one-dimensional men" (28)

Other constituent elements of this articulation with the critical theory for the analytical component of bioethics came from a much more recent author, strongly influenced by critical theory: Robert Cox (29). This author maintained that the process of globalization, consolidated in the last decades of the twentieth century, would have resulted in the internationalization of nation-states and in the formation of a dominant transnational civil society, as a result of the concentration of wealth.

It would then have a kind of global governance without government, which he called a ''nebula'', that constituted a central feature of the world order. This order clearly favored groups that had instrumental control over three forces: 1. material capacities, represented by financial resources and means of production; 2. ideas, represented by inter-subjective notions that perpetuated habits, behaviors, and collective images that legitimized power, including their own scientific and moral ideas; and 3. institutions, including the various apparatus of central countries and international non-governmental bodies. These institutions were responsible for articulating ideas and material capacities with a view to stabilizing and perpetuating the world order.

For Cox (29) individuals and groups were divided into three fundamental categories regarding their access to the benefits of the globalized world order: 1. the integrated, who are members of internationalized civil societies either by holding power or being favored by it; 2. the precarious, who have some access but face difficulties and deficiencies dependent on the fluctuations of the order; and 3. those who are unable to consume the products and are not even considered.

Ultimately, critical bioethics produced in Latin America could not avoid a geopolitically located perspective, given that biotechnologies are produced and distributed by central countries under norms developed within power dynamics that invariably favor the interests of those same countries. Hence, the model of colonial studies is important.

The concept of "coloniality" was developed by Peruvian sociologist Aníbal Quijano (10) in the late 1980s and early 1990s. Coloniality refers to the persistence of colonial logic structuring the relationship between central and peripheral countries regarding the exercise of power and the production of knowledge. It is seen as constitutive of modernity itself, as the notion of modernity itself, as the notion of modernity was built on the opposition between colonizers and colonized, with the former representing progress, innovation, development, and the center of the world, and the latter representing backwardness, archaicism, stagnation, and the periphery.

In this process, the notion of race became a central element, as the ''civilized'' European white person was considered the pinnacle of human evolution, in contrast to the perceived biological, mental, and moral inferiority of the colonized people, whether indigenous or African. The concept even justified Christian evangelization and the economic model based on the exploitation of resources and slave labor in the colonies.

Thus, categories intrinsic to European modern thought, such as "universality" and "rationality", were developed in a colonial manner, with the European white person as the standard of universal and rational humanity. Similarly, notions of development and progress were framed by global norms that have operated since the beginning of colonization, ensuring the flow of raw materials from the periphery to the center and technological products from the center to the periphery. Currently, for authors like Quijano (Quijano, 2007), Mignolo (Mignolo, 2011), and Grosfoguel (Grosfoguel, 2002), coloniality represents the ongoing imposing of central countries' power over peripheral countries.

Decoloniality, therefore, encompasses studies, thoughts, processes, and actions aimed to overcoming coloniality historically. In other words, it involves political, socioeconomic, ethical, and esthetic analyses and practices that challenge the colonial pillars of modernity. According to Mignolo

(Mignolo, 2011), decoloniality represents both a political and epistemic project.

The articulation of the concepts presented thus far forms the theoretical framework underlying the analytical component of decolonial critical bioethics, integrating deeply with robust social theories, as supported by the authors of critical bioethics discussed (Parker (1); Hedgecoe (6) Twine, 2007; Árnason, 2015; Cunha and Lorenzo, 2014).

Next, this project will address the fundamentals for the prescriptive component of decolonial critical bioethics. Árnason (Árnason, 2015) highlighted the importance of a well-founded performance in public spaces where normative deliberations in bioethics are formulated. Armasón advocated for communicative rationality as ideal for conducting discussions from which normative deliberations are derived. Previously, however, the decolonial critical bioethics model had already proposed that discussions in public spaces typical of bioethics, such as research ethics committees, hospital bioethics committees, national and international bioethics commissions, and biosafety commissions, should be guided by parameters of communicative action (Cunha and Lorenzo, 2014; Lorenzo, 2012). This proposal is rooted in Habermas' central work, *Theory of Communicative Action* (Habermas, 1981), where he defines and elaborates on the concept of communicative rationality.

In the *Theory of Communicative Action* (Habermas, 1981), Habermas establishes the foundation for a new form of *rationality* for social actions, known as *communicative* rationality. This form of rationality is intended to offer resistance to the purely instrumental rationality of economic and political powers. The practice of communicative rationality depends on the establishment of a *communication community*, formed by public, democratic spaces for discussion and the development of conditions for mutual understanding among social actors.

Therefore, an argument or norm has a hypothetical claim to validity when it can be justified rationally. A norm should seek a *status analogous to truth*; in other words, coherence between the action it directs and the nature of the *social fact* that it aims to regulate.

The three criteria that determine this *claim to validity* are: the *truth of the proposition*, the *rightness of the actions prescribed*, and the *authenticity of the social actor*. The first criterion requires that the norm, when addressing aspects of reality related to verifiable truths, be supported by scientific or statistical data, (constituting the empirical grounding of the proposal). The second criterion requires that norms be compatible with the socio-cultural context to ensure their compliance. Finally, the third criterion pertains to the *subjective world* of each participant in the normative deliberation and requires that each social actor be receptive to the rational strength of the arguments, without adhering to religious, ideological, or disciplinary dogmas, without being subjected to hierarchies, without hidden third-party interests, and without employing spurious language tactics such as induction, coercion, or deceit. When these three criteria are met, the proposed norm is likely to be accepted by all those involved in the social fact to be regulated.

Thus, decolonial critical bioethics is sociologically grounded for analytical practices from a perspective partly specific to peripheral countries in relation to the world order. It examines the contexts, ideologies, and powers (31) involved in the ethical issues related to the production and distribution of biotechnologies on a global scale. Regarding the operationalization of deliberative processes that define normative propositions, the model offers guidance based on communicative rationality, while being attentive to decolonial critiques concerning the potential ethnocentric understanding of rationality.

The analytical parameters of critical bioethics can be summarized in six statements:

1) International relations in the field of global health are understood as historical and geopolitical colonial processes that produce global hierarchies of politics, culture, morals, epistemics, aesthetics, class, gender, and race. This ensures control of the production and dissemination of knowledge by central countries and maintains a continuous flow of raw materials from the periphery to the center and industrialized

products from to the center and industrialized products from the center to the periphery.

2) The world-system is structured by the instrumental control of three forces: a) material capacities; b) ideas, whether scientific, normative, or aesthetic; and c) national and international institutions responsible for articulating the action of the two previous forces, ideas and material capabilities.

3) The examination of the political quality of governance, the dependence of governmental and non-governmental institutions on the world-system, socioeconomic disparities, and access to health across countries must be understood as the results of these historically determined global hierarchies.

4) There is no ethical or ideological neutrality in science. Scientific interests are increasingly linked to economic interests and are driven by the formation of the industrial scientific-technological complex, which produces a naturalization of its results and favors an uncritical and unidimensional view of the world.

5) Ethical conflicts must be understood as social facts that can be transformed. The objective of decolonial critical bioethics is to identify the elements that generate the conflict and explore possible ways for its prevention or resolution.

6) The normative production process in public decision-making spaces, whether institutional, state, or non-governmental international, must be conducted based on communicative rationality.

Decolonial critical bioethics in action: Analyzing the disparity in access to the clotting factor concentrate by populations of hemophiliacs in the Americas

The World Federation of Hemophilia (WFH) employs the per capita use of clotting factor concentrate by the population of hemophiliacs in one year to estimate access and quality of care. A per capita / year rate of less than 1.0 IU is considered to be implicated in very low survival. The preservation of joint function and the promotion of a quality of life close to that of a non-carrier require rates equal to or greater than 3.0 IU per capita / year. The data presented here are from the WFH's last report published in 2018 (13).

The WFH estimates that only 25% of hemophiliacs in the world have appropriate treatment. WFH annual reports draw attention to the seriousness of situations in countries where the per capita income is less than $ 995 / year, in which factor use rates are less than or equal to 0.04 IU per capita / year. The situation may be even more serious than is represented numerically in these countries, given the difficulties of their health systems in generating records and information. In many peripheral countries, population access depends exclusively on international donations (32)..

Disparity in access is very clearly expressed in the countries of the Americas. While in two central countries, Canada and the United States, the rate is 8.15 and 9.96 IU per capita / year, respectively, in all Central American and Caribbean countries it varies from 0.23 to 0.78 IU per capita / year among the countries studied, except for Costa Rica with a rate of 3.16 IU. The Dominican Republic has the lowest rate in the Americas, at 0.52 IU per capita / year. Panama and Mexico follow with very low rates, having 0.42 IU and 1.82 IU per capita / year, respectively. The two countries that approach the satisfactory baseline are Venezuela, with 2.49, and Chile, with 2.95 IU per capita / year. Four countries manage to surpass this mark: namely, Costa Rica with 3.23, Brazil with 3.55, Argentina with 4.38 IU, and Colombia with 5.08 IU per capita / year (Boadas *et al.*, 33). With this in mind, it is important to consider the regional socioeconomic disparities within these countries that may not guarantee internal equity in access. In Brazil, for example, a study in 2014 showed that the Federal District's rate of use, which contains the country's capital, was 13.27 IU, while in the State of Maranhão, in the northeast of the country, it was 1.96 IU per capita / year (34).

In summary, among the twenty-three countries studied by the WFH report, thirteen had rates below 1.0 IU per capita / year, and two exceeded it by a few tenths, showing the severity of the exclusion

of access to the factor concentrate. The disparity is well represented by the fact that the United States and Canada have indices about three times higher than the satisfactory minimum level of 3.0 IU, while in eight countries, it is about three times less than the minimum reference value of 1.0 IU per capita / year, which is already associated with very low survival.

No country in Latin America or the Caribbean has the technology to produce factor concentrates and depends entirely on imports or assistance programs. The high price charged by the oligopoly formed by the twelve companies on the planet that dominate the production of factor concentrate is the key element highlighted as an obstacle to access (35). Three of these companies, uncoincidentally, are located in countries with the highest rates of use, two of them being in the United States and one in Canada, which increases the processes of exclusion (36).

The outlined panorama largely reflects the historical results of domination. Through economic dependence and central countries' typical colonial interference in the choices and forms of governance of peripheral countries in the Americas, this domination is renewed in contemporary times. This hierarchy is reinforced by the centralization of scientific production and the scarcity or lack of technology transfer programs.

Furthermore, the unidimensionality of thought, characteristic of industrial societies, favors a collective posture among health professionals and researchers of generally being extremely uncritical and immature, with poor ethics discussions in universities regarding the social impacts of their work. This reduces the performance of other social actors in the ethical and political confrontation of these inequities (37,38).

Thus, the data presented reflect the instrumental control of the three forces that structure global power, as understood by Critical Bioethics: material capacity, ideas, and institutions. In this context, material capacity refers to the domain of scientific and industrial equipment and the raw materials needed to produce the factor concentrate. The domain of ideas refers to both those linked to the generation of scientific knowledge and those that make it possible to extract the factor from human plasma or produce it by genetic engineering. It also includes ideas that influence the international rules for the production and commercialization of medicines and supplies. An example of such ideas is the current moral status of the freedom of industrial production and commercial profit, which is placed above the moral status of the right to health and life, as enforced by the TRIPS agreement of the World Trade Organization (39, 40). Lastly, with respect to institutions, this domain is exercised both in relation to producing institutions such as universities, research centers, and biotechnological industries, and in relation to standardization organizations, such as governmental bodies and non-governmental international organizations.

Given the unquestionable fact that the worst health conditions affect Black and Indigenous populations in the Americas, and that structural and institutional racism negatively impacts the quality and access to health care, it cannot be excluded that these disparities are also permeated by a devaluation of the human, closely related to the greater degree of miscegenation among the affected populations. Therefore, the ethical conflicts presented in this study arise from the global hierarchies that structure the colonial world-system. Their solutions constitute extremely complex challenges, as they imply transforming the very exclusionary and centralizing economic development model within which relations between countries are established.

Obviously, overcoming these challenges is far beyond the possibility of a single discipline, but they can be addressed from the perspective of critical bioethics. This involves intensifying scientific production capable of supporting necessary confrontations with governmental bodies and international organizations. Such confrontations can favor fairer regulations in the production and sharing of health technologies. Supported by scientific evidence, these confrontations can also promote the development of international cooperation programs for technology transfer that can change health realities, providing autonomy to countries without the hegemonic charity aspect

that reaffirms and legitimizes the superiority of some countries and people over others.

Final considerations

In our view, bioethical analytical and standardizing practices around issues related to access to health care for populations, as well as other global bioethics issues such as environmental destruction, hunger, demographic explosion, and pandemic approaches like COVID -19, are enriched when applying a hermeneutics of ideologies and power dynamics around through a theoretical and epistemological perspective of the countries most frequently affected by health exclusion, particularly those in the geopolitical South.

The ethical and political dimensions of exclusion, along with the commitment to equity and the fulfillment of the human right to health, impose great responsibilities on states, companies, society, and particularly the scientific community. In the specific case of hemophilia, it is necessary to look beyond the numbers and graphs that show low rates of access to factor concentrate to the suffering of thousands of children living painful lives awaiting early deaths, and adults who, having survived such childhoods, are incapacitated to work, burden their families, many of whom are already affected by poverty.

Awareness of this reality should be sufficient to mobilize states and international non-governmental organizations in health to establish more horizontal international cooperation projects between central and peripheral countries, capable of guaranteeing more dignified treatment and a better quality of life for hundreds of thousands of hemophilia patients worldwide.

Faced with these historically determined inequities, maintained by the current colonial world system affecting not only hemophilia but a vast array of rare and neglected diseases, the commitment of decolonial critical bioethics must focus on scientific productions aimed at the emancipation of those who suffer physically and mentally from the perverse effects of health exclusion. Bioethics, in general, must support programs, policies, laws, and other normative documents that guide the production and access to life-saving technologies.

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