

**RESEARCH**

Current challenges of the Brazilian bioethics

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Abstract

This study aims to analyze the current challenges of bioethics in the Brazilian perspective. This is an analytical-exploratory study with a qualitative approach and a social-historical perspective. The semi-structured interview technique was applied. The selection of participants (14 Brazilian bioethics researchers) was performed by convenience and snowball sampling was used. Four axes emerged from the results: Characteristics of the Brazilian Bioethics; the Challenge of overcoming borders; the Challenge of bringing politics to bioethics; and Academic challenges for Brazilian Bioethics. It is concluded that, as a process in permanent transformation, Brazilian Bioethics has overcome several obstacles from the beginning of the discussions and, as it progresses, it grows as a field of knowledge and political action.

Keywords: Bioethics. Brazil. Politics. Ethics. History.

Resumo**Desafios atuais da bioética brasileira**

Este estudo tem como objetivo analisar os desafios atuais da bioética no Brasil. Trata-se de pesquisa exploratória, analítica, de abordagem qualitativa e perspectiva histórico-social. Utilizou-se a técnica de entrevista semiestruturada, e a seleção dos participantes (14 pesquisadores brasileiros) se deu por conveniência e amostragem por bola de neve. Dos resultados surgiram quatro eixos: características da bioética brasileira; desafio de ultrapassar fronteiras; dificuldade de aproximação à política da bioética; e introdução desse campo do conhecimento no âmbito acadêmico. Concluiu-se que, como processo em permanente devir, a bioética transpôs diversas barreiras desde que chegou ao país e, à medida que avança e se constitui como campo de conhecimento e ação política, novos desafios se apresentam.

Palavras-chave: Bioética. Brasil. Política. Ética. História.

Resumen**Desafíos actuales de la bioética brasileña**

Este estudio tiene como objetivo analizar los desafíos actuales de la Bioética en Brasil. Se trata de una investigación exploratoria, analítica, de abordaje cualitativo y con perspectiva histórico-social. Se utilizó la técnica de entrevista semiestructurada. La selección de los participantes (14 investigadores brasileños) se realizó por conveniencia y el muestreo por bola de nieve. De los resultados emergieron cuatro ejes: características de la bioética brasileña; desafío de atravesar las fronteras; dificultad de aproximación a la política de la bioética; e introducción de este campo de conocimiento en el ámbito académico. Se concluye que, en tanto proceso en constante devenir, la bioética transpuso diversas barreras desde que llegó al país y, a medida que avanza y se constituye como campo de conocimiento y de acción política, se presentan nuevos desafíos.

Palabras clave: Bioética. Brasil. Política. Ética. Historia.

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Derived from the biosciences and technologies, bioethics is a field in which important reflections are projected on the consequences of human action for life. By creating privileged space to discuss impacts of scientific-technological development, bioethics becomes cognitive and emancipatory praxis that drives the way of doing science responsibly and competently¹. The knowledge coming from this field originates from a historical period of scientific and technological innovations in which many were the paths proposed by important characters for the conquest of knowledge and fields of action².

There are several ways to revisit the history of bioethics, and many are the nuances of each context or period; thus many stories could be written. Nevertheless, there are intersections or sharing of facts, theoretical amalgams and interests, a sort of common accumulated or at least translatable baggage, with broader and more mobile meanings. In other words, from the much that is spoken about or on behalf of bioethics from different places, much of it makes sense beyond contexts and discourses, with increasing scope for discussion and appropriation.

Since the 1990s, in Brazilian and world literature, studies have analyzed bioethics from different perspectives³⁻⁵; among many examples, the pioneering historiographical work of Jonsen⁶ stands out. However, more historical research is needed so that inventories and classifications can be made under different ordering keys or axes, mapping conceptual propositions and impacting events, as well as researchers and disseminators, within areas such as law, biology, and medicine or the more normative scope of bioethics at the political-institutional level⁷.

About the Ibero-American context, Pessin and Barchifontaine⁸ analyze four decades of history (1970-2007) in the work *“Uma radiografia da bioética no Brasil”* (An x-ray of bioethics in Brazil). The authors highlight intellectual leaders in this field, emphasizing the Latin American context, from reflections mobilized by pioneering voices from ten countries, demonstrating the breadth of bioethics in the region and addressing their relations with the theme of religion and women.

To this historical perspective, the present article intends to add a prospective look, questioning what is ahead by proposing challenging questions about the future of bioethics in this regional context. The objective is to analyze the challenges to bioethics in the country as a field of knowledge and political

action from the perspective of Brazilian scholars considered precursors. The basic assumption is that we can talk about Brazilian bioethics, with its own nuances and commitments, influenced by international references and global issues, which has assimilated ideas and is committed to overcoming gaps and problems inherent in the country's political and social reality.

Method

This is an exploratory, analytical study with a qualitative approach that seeks to elucidate the lived context and its meanings, not limited to the chronological report of the facts, but aiming at historical criticism⁹. The oral history technique¹⁰ was adopted as a resource capable of writing stories of the present time, recognized as alive and democratic, giving voice to different narrators and recovering what is missing in documents, such as unclear events or personal and private experiences¹¹.

The study included 14 researchers and professionals from different areas, such as theology, humanities, and health, considered in the scientific environment as precursors of discussions about bioethics in Brazil due to their research, publications, and performance in institutional spaces. The snowball technique of sampling selection was used. A researcher with national and international recognition and vast scientific production was invited to participate in the study and, in his interview, indicated other important names in the trajectory of Brazilian bioethics. Subsequently, each respondent recommended new participants, who were invited to the survey, until data saturation.

Data collection was performed between October 2012 and December 2013, through semi-structured interviews. The content was transcribed and sent for validation to participants, and only one of them did not approve the transcript. The study, therefore, includes 13 interviews.

The data were organized with the aid of the Atlas.ti software, which builds thematic characteristics by content similarity. The Informed Consent Form (ICF) and the copyright assignment document were signed by all respondents. The code “interviewee” was used, followed by a numerical order from 1 to 13, to identify participants in excerpts extracted from the statements.

Results and discussion

The testimonies, discursive contexts, some interpretations and contributions from bibliographic sources were worked from categories organized in four axes.

Characteristics of Brazilian bioethics

To introduce the theme of current challenges, it is necessary to take up the context that makes Brazilian bioethics peculiar, paying attention to its expansion and retraction cycles. Some particularities are highlighted in terms of advancement, criticality or simply differentiation from international hegemonic aspects:

“Brazilian bioethics, in general, followed a slightly different path from international bioethics. It has always been more critical (...). It has a more horizontal and less vertical proposal for things” (E1);

“Latin America is different from Europe and the United States and Canada. (...) Here in Brazil, several [researchers] are linked to public health. This is an interesting feature.” (E4).

At the beginning of the bioethical discussions in Brazil, the militancy of the interviewees and the scenario of re-democratization created the expectation that the new field would be a useful tool to reach political, collective goals, sensitive to the needs of great changes. The critical character is pointed out in the emergence of bioethics in Brazil by recognizing its strong link with social movements in defense of democracy, social and civil rights, and the large portion of the socially disfavored population. The hallmarks of this origin operate both as breaking points and as consolidating discourses and practices:

“Brazil has a very interesting feature when we meet Latin American colleagues. Multiple factors determine this. In most Latin American countries, bioethics is almost exclusively medical, closely linked to medical schools and the medical profession” (E4).

The relationship between Brazilian bioethics and health reform, or the struggle for the right to health is exemplary, since the field does not seem to have been hampered by the interests of medicine, but rather has a useful space for diffusion.

Besides the political context and its multidisciplinary aspect, another characteristic that marks the beginning of bioethics in Brazil is the ability

to produce new thoughts and aggregate multiple subjects. This last point is seen today by many as weakened, generating some disappointment and demand for new directions. After the time of expansion, thriving debates and rapid increase of forums, actors and discussions, the interviewees denounce the current moment as stagnation, repetition, and disarticulation, precisely when many interlocutors and scholars raise expectations for new and strengthened bases:

“[We are] in a period in need of rethinking Brazilian bioethics. We have expanded a lot. The Latin American movement expanded jointly. Argentina has a history in bioethics prior to ours. Chile, a little bit, but still, there are important people” (E4);

“I think Brazilian bioethics had a boom. There are still people who want to work with bioethics, but it has stopped in time. This is a moment of stagnation. (...) But we have everything to leverage this because there are many researchers, many graduate students. Now, maybe the way this theme is being worked out is not the best, you drive people away” (E12).

Far from having a unique origin and historical direction, Brazilian bioethics brought together different actors, catalyzing secular and religious perspectives and political-social movements and claims for changes in the academic setting. These perspectives and movements did not constitute a unity, but were solidified in interests and principles, most visibly in terms of popular organization and the construction of broad reform of the health system. However, if tasks are unfinished, and so many potentials have been glimpsed, why the apparent paradox between expansion and stagnation?

The challenge of crossing borders

The challenge of crossing borders can be seen from different perspectives. The first, geographic, concerns the desire of researchers to increase the visibility of Brazilian bioethics in international spaces. The wide range of interests of Europeans, Americans, and Latin Americans is due to socio-cultural and economic development differences and issues related to the production of bioethical knowledge, historically later in peripheral countries:

“[Brazilian bioethics] has no international visibility yet, but in the Latin American context, we already have good visibility. I have been trying to attend

international meetings and have had some strong clashes on controversial issues related to social exclusion, vulnerabilities, different forms of discrimination, among other issues” (E1).

Despite the growing space of scientific production, Brazilian studies still do not circulate globally. The challenge is twofold: to consolidate the country as a recognized reference producer and to raise awareness of issues still outside the international agenda. These difficulties have been the object of complaint by the scientific community in different areas, given the greater acceptance of scientific publications from central countries compared to peripheral countries. Despite the obstacles imposed by the international political-scientific scenario, researchers and authors of Brazilian bioethics work to promote current themes of the national social, environmental and technological context¹²⁻¹⁴.

Another frontier for the expansion of Brazilian bioethics refers to the limits of its discussions, which take place in restricted spaces, such as universities and health and research organizations. The way to make bioethics the foundation for everyday practice, present in different instances of the social fabric, is still arduous. Bioethical knowledge as a tool for emancipating practices, equity and justice is an objective image.

Due to its history, loaded with commitments to the political transformations needed at the moment of its appearance, Brazilian bioethics created for itself a social image, considered fundamental by the interviewees. For them, the critical perspective must materialize in practical life and daily relations, with a policy that requires permanent negotiations, disputes and clear options backed by collective interests:

“What I got in return when I was presiding over the elaboration of the 196 [CNS Resolution 196/1996] was listening to the segments of society. This was of such great wealth and it was what allowed the 196 to succeed (...). So, it is in society that we have to work” (E3);

“I wish we could turn bioethics into everyday practice. I am an anarchist, I believe in everyday practice” (E13).

When the look is directed to the past or the future, there is strong recognition of the potential of education and leadership formation capable of broadening the impact of the reflection of bioethics

in its relations with different fields of knowledge and sectors of society. From the 1990s, when the first specialization course in bioethics was created in Brazil to the present day, there was a significant increase in *lato* and *stricto sensu* postgraduate offer in different regions⁸. The expansion of the offer of courses especially focused on bioethics as a field of knowledge reflected in the reach of new audiences. The challenge now is to push academic boundaries and reach other spaces of society.

“We would settle in courses around Brazil, discuss in society (...). I prepared course projects in Brazil, but we couldn’t. There are several places where it is still crawling or has been appropriated by deontological thinking” (E4);

“Now you have to move to another segment of society, and I think we’ll start working with young people. (...) We should act before the individual enters the university” (E3).

All spaces are of great relevance to concrete mediations. Bioethics assumes a strong social character by providing possibilities for intervention with citizens, and its bridge with society is fundamental for building knowledge and transforming reality¹⁵.

A possible tool for socializing the discussions of bioethics is the media. A discursive field without visibility and limited to a few unusual themes is enclosed in expert opinions on issues brought to light only by exceptional events. Thus, the national press only reproduces the misunderstanding as to the meaning, importance and field of interest, and intervention of bioethics.

“You have great bioethics features, but you don’t see [the word] ‘bioethics’ in the headlines (...). If you take La Repubblica newspaper in Italy, the New York Times, or Spain’s El País, the main call is ‘bioethics’ (...). That is, Brazil is still far behind in understanding what bioethics is (...). The New York Times recently made a long article on the ten most important prospective themes of the 21st century, and Bioethics was one of them” (E1);

“At our last congress, in 2011, we brought over 30 foreigners to Brasilia. The press once again did not show up (...). So, this lack of visibility is also related to the misunderstanding of the Brazilian press about bioethics” (E1).

Here we can point out the paradox of the information society, which allows the extreme

dissemination of bioethical themes, but which faces the risk, uncertainty and the breakdown of full confidence in knowledge⁷. In this society, where institutions are constantly undermined by credibility, unsubstantiated opinions overlap with stronger research results. The paradox lies in the frustration of the bioethical ideal as a tool for social practices (political, scientific, academic, legal) and as a mediating and argumentative instance, disappearing as a collective and interdisciplinary effort to be overshadowed by the momentary interest of the news.

The challenge of “bioethicizing” politics

By using the verb “bioethicize”, we do not intend to coin a neologism, but to reflect on bioethics as the basis for relevant political discussions. Therefore, it is not a matter of politicizing the bioethical discourse, but of inserting it in the agenda of the political agenda. For this, according to the interviewees, it would be necessary to create the Conselho Nacional de Bioética (National Bioethics Council), or Comissão Nacional de Bioética (National Commission of Bioethics), an institution that would define guidelines for themes of an essentially ethical/bioethical nature, broadening the perspectives beyond the legal, economic or medical-scientific foundations:

“The Bill that proposes the creation of the National Bioethics Council has been in the National Congress since 2005, and this is a shame for Brazil. All countries in the European community already have their councils (...). The Brazilian project was wonderful (...) it was very democratic (...)” (E1);

“The great challenge, I see, in political terms, is to have a National Bioethics Commission (...) This is a very serious challenge, especially in the political context in which we live. How would you guarantee a democratic space for things to be democratically discussed as they are in other committees?” (E9).

While paving the way for the future, accelerated scientific and technological development in recent decades raises political, economic and social issues that need to be discussed collectively. In this perspective, we can see the importance of committees, commissions or councils of bioethics, spaces that have the challenge of building societies founded on democracy and justice.

Most developed countries already have their national bioethics committees or councils, examples of positive experiences of dialogue and negotiation

between differently thinking people and groups¹⁶. At the time of data collection in this study, it was one of the fronts Sociedade Brasileira de Bioética – Brazilian Society of Bioethics (SBB) to mobilize for the creation of a national council, arguing that this achievement, through dialogue with government, congresspeople, and society would reduce the interference of political interests in ethical issues⁸.

The researchers’ proposal is not to address ethical dilemmas of justice in terms of politics, but the opposite: to think of politics in terms of fair solutions for society. Today bioethics faces the challenge of creating spaces for rational dialogue, but it is hampered, as it lacks support from political systems, which suffer from a crisis of political representation and partisan credibility¹⁷. Moreover, the difficulty of those involved themselves with bioethics in Brazil in joining forces to overcome this problem:

“I think that, if we thought that this [National Bioethics Commission] was really important, we would be fighting for it to happen. We have no political strength. I’m feeling it, it’s kind of quiet. Also because people are aging, some people are leaving the scene, and these people did not provide for a new generation (...)” (E12).

In addition to the national level, scholars have also highlighted the importance of consolidating regional bioethics committees and centers in different areas of interest as legitimate spaces for deliberation. The success of research ethics council experiments may be a precedent to believe in the potential of these collegiate spaces:

“It could be said that, just as there are hospital bioethics committees, there should be a primary care bioethics committee in the municipalities, of which the supporter should be part to be a facilitator of this discussion in the teams” (E11);

“The Regional Council of Medicine of the State of São Paulo had the initiative to create a bioethics center (...). The center has an activity very closely linked specifically to bioethics and very closely linked to clinical bioethics (...). We have some publications (...). It is an initiative that I would like to be reproduced in other councils (...)” (E10).

Clinical or hospital bioethics committees were initially created in the United States from the 1960s onwards. Today, in addition to consolidated spaces for discussion, they contribute to institutional policies and education actions related to clinical

ethics. After the U.S. experience, committees were created in Europe and Latin America, although with less repercussion. In Brazil, the first committees were established only from the 1990s. However, although they have become an important tool for identifying and responding to ethical dilemmas in hospitals, there is no legislation in our country that regulates the creation and activities of ethics committees¹⁸⁻²¹.

There is yet another challenge: the evolution from hospital bioethics to social bioethics. Although this field of knowledge has been introduced in various socialization spaces and especially in the health sector, it has been very difficult to overcome local political issues to modify decisions of those responsible for mediation and conflict resolution in the care system²². The implementation of bioethics centers stands out as a positive experience, but the challenge of extending it to other spaces linked to professional practice remains.

In Latin America, since 1999 we have the Instituto de Bioética, Direitos Humanos e Gênero – Anis (Institute of Bioethics, Human Rights and Gender), the first non-governmental organization dedicated to research, advice, and training in bioethics. The institution, registered in 2002 with the Conselho Nacional de Desenvolvimento Científico e Tecnológico – National Council for Scientific and Technological Development (CNPq), executes its actions through four programs that have several objectives: one of them is to disseminate and democratize the information on bioethics in Brazil⁸.

Academic challenges for Brazilian bioethics

From the perspective that brings the academy closer to bioethics in the sense of training in this field of knowledge, the interviewees pointed to the challenge of expanding the offer of postgraduate courses, especially *stricto sensu*:

“At the academic level, there are only three stricto sensu graduate programs in Brazil [São Paulo, the Federal District, and Rio de Janeiro]. It’s too little! Brazil currently has a huge number of interdisciplinary and health postgraduate programs controlled by Capes [Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (Coordination for the Improvement of Higher Education Personnel)]. I believe there are more than 700 today (...). And having only three bioethics is too little (...)” (E1).

It should be noted that, because it dates from 2013, the statement by E1 does not cite the *stricto sensu* postgraduate program of the Pontifícia

Universidade Católica do Paraná (Pontifical Catholic University of Paraná), which started its master’s degree course in the same year. Postgraduate courses in bioethics are recent in Brazil and, despite the advances in the last 20 years, it is still a great challenge to consolidate the field as a discipline of theoretical and philosophical reflection. Some shortcomings are filled by courses that offer bioethics-related courses – in 2009 there were 163 of these courses – and also by *lato sensu* specialization, which has increased significantly in several Brazilian universities²³⁻²⁵.

In this context, concern was identified about the investment in the training of researchers, since educational processes are fundamental in the diffusion of knowledge related to bioethics. Documentary research on the teaching of bioethics in postgraduate health courses in Brazil found a significant number of teachers without specific training, either in *lato sensu* or *stricto sensu* postgraduate courses^{19,24}:

“We have a huge challenge to train teachers, because (...) the subject matter exists, we recognize its need, and well-meaning people take it almost on their own and start teaching and become bioethics teachers. But we do not have this line of training in the country (...)” (E13).

Postgraduate training is pointed out as an obstacle, which encourages the multidisciplinary and interdisciplinary training of professionals. However, it is argued that postgraduate education is insufficient to meet the demands of society since bioethics has a transdisciplinary character^{26,27}. Another important issue would be how to articulate scientific with humanistic cultures and to create a method for teaching bioethics²⁸.

If, on the one hand, there is the complexity of expanding the offer of academic education in bioethics, on the other, new challenges arise to absorb and give visibility to scientific productions. In this sense, there were several manifestations of respondents regarding the creation and strengthening of scientific journals on bioethics, to absorb the demand of graduate programs and reach different audiences, considering the interdisciplinarity of the field and its potential contributions. In 1993 the *Revista Bioética (Bioethics Journal)* of the Conselho Federal de Medicina (Federal Council of Medicine) was created; twelve years later (2005), the *Revista Brasileira de Bioética (Brazilian Bioethics Journal)* of the Sociedade Brasileira de Bioética (Brazilian Society of Bioethics),

and shortly after that (2007) the *Bioethikos* journal of the São Camilo University Center in São Paulo²⁵.

The work to consolidate these journals has been arduous, as it is necessary to maintain the regularity of publications and to ensure quality based on national and international editorial criteria. Despite advances, journal funding and rating agencies do not operate according to criteria sensitive to the specificities of each area. Not all fields of knowledge have representation in the areas established by these agencies, and journals from other, multi-professional, domains, do not always recognize and welcome bioethical productions as their own. Such restrictions on studies of a growing contingent of researchers and the limits of the classification of journals that reach science, both Brazilian and worldwide, are in disagreement with the important contribution of bioethics journals.

Final considerations

From the history of Brazilian bioethics told by subjects who have contributed to the field since its origin, the need to project challenges for the future also arose. It is expected that the word “current” used in the title of this study will be overcome, and what are challenges today, will become achievements tomorrow.

The trajectory of bioethics in Brazil is solidary with social expectations, and the constant challenges relate to the difficulty of effectively meeting collective interests, creating praxis inserted in the fight against inequalities, in search of democratic legitimacy. Overcoming these obstacles requires mechanisms to include bioethical discussions in the spaces where public policy directions are defined. Moreover, only by broadening the spaces for concrete interventions will it be possible to transform the reality of citizens and resolve ethical conflicts related to health and adverse situations arising from technological advances, shedding light on emerging themes in peripheral and central countries.

The capillarity of the Brazilian production in international contexts is still small. The specifically bioethical scientific dissemination instruments are not yet consolidated. The emergence of graduate programs and the training of specialist professionals create expectations of change in this scenario. Production from such programs, which will support the academic corpus of Brazilian bioethics, will require ways of absorbing the knowledge produced and incorporating it into practical changes. Naturally, Brazilian bioethics has crossed several barriers since the beginning of its discussions, and as it advances, becoming a field of knowledge and political action, new challenges are presented.

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Participation of the authors

Laura Cavalcanti de Farias Brehmer collected the data. All authors conceived the study, analyzed and interpreted the data, and contributed to the critical review of content and final approval of the article.


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Annex

Interview roadmap

Project: The history of bioethics as a field of knowledge and political action in Brazil

- a) What is your first memory of the term bioethics?
- b) Could you describe the professional moment and the political and academic context in which you first came into contact with Bioethics?
- c) From this first contact, how did you develop your approach to this field?
- d) Do you recognize events, leaders or spaces that were important for the emergence of bioethics in the Brazilian scenario? Could you report them from your experience?
- e) In your view, what characterizes the specificity of the emergence of bioethics in the Brazilian political, academic and scientific context? Could you highlight moments of the history of bioethics in each of these contexts or interfaces (political, academic and scientific)?
- f) What were your contributions or participation in this Bioethics scenario?
- g) Which people have transited with you or are recognized by you in the development of Bioethics in Brazil?
- h) Space to add any other information you deem important.

Note: Pre-interview in which copies of photos, documents or notes will be released to the subjects, that may contribute to the composition of the historical collection that will be assembled during the study and that can illustrate the reports.