

Diego Carlos Zanella\*

# Is the Brazilian Made Bioethics Social? A Personal Account

## SUMMARY

This paper aims to present the panorama in which bioethics was found in Brazil. For this, exploratory descriptive and documentary research will be carried out on the emergence of bioethics as a field of research and its process of institutionalization in Brazil. In this sense, three facts are very significant: i) the creation of a bi-annual journal, *Revista Bioética*, published by the Federal Council of Medicine (CFM) in 1993; ii) the creation of the Brazilian Society of Bioethics (SBB) in 1995 to bring together researchers and people from different academic areas interested in bioethics; and iii) the edition of Resolution N.º 196 of October 10, 1996, of the National Health Council (CNS), which created the Brazilian Research Ethics System, that is, the Research Ethics Committees (CEP) and the National Research Ethics Commission (CONEP). These three facts will allow to identify which are the main defining elements and how they form the first theoretical models of Brazilian bioethics. Thus, this research will allow the building of a panorama of Brazilian bioethics, in which the characteristic notes of such a bioethical thought will be identified.

**Keywords:** Brazilian Bioethics, History of Bioethics, Vulnerability, Social Bioethics.

## Introduction

Developing research on the history of bioethics in Brazil presents some adversities, not of a conceptual, interpretive or methodological nature, but mainly about the experience and monitoring of this process, documented in “a dispersed and a little disseminated” way.<sup>1</sup> Several publications deal with history, institutionalization and bioethical theories in Brazil. However, these works are rarely comprehensive, seeking

\* *Correspondence Address:* Diego Carlos Zanella, Department of Philosophy, Faculty of Humanities, Universidade Franciscana (UFN), Rua dos Andradas, 1614, Santa Maria, RS, Brazil. E-mail: [diego.zanella@gmail.com](mailto:diego.zanella@gmail.com). ORCID ID: <https://orcid.org/0000-0002-2180-4011>.

1 Braga, Kátia Soares and Diniz, Débora (2002), Introdução, in: Braga, Kátia Soares ed. (2002), *Bibliografia bioética brasileira: 1990-2002*, Brasília, Letras Livres 2002, p. 10.

to account for the complex totality of such a process. In the vast majority of cases, such publications deal with more specific issues that were intensely experienced by their authors. This is not the case with me, as I approached bioethics only very recently, starting in 2013.

The ethical concern about life has always been a fascinating topic for me, especially since my biology classes in high school but which I somehow neglected during my formative years in philosophy. This topic only became the focus of my interest again in August 2012, when I started teaching at the *Universidade Franciscana (UFN)*<sup>2</sup> in Santa Maria, in the state of Rio Grande do Sul, Brazil, where I currently live and work. The need to teach the curricular component 'bioethics' demanded specific knowledge that I did not have. This made me search for such knowledge initially in an autonomous and solitary way and later, from August 2015, in the Bioethics Program of the *Facultad Latinoamericana de Ciencias Sociales (FLACSO)* in Buenos Aires, Argentina.

My studies in bioethics range from knowing its history, whether with the appearance of the term in the United States by Van Rensselaer Potter (1911-2001),<sup>3</sup> or in Germany by Fritz Jahr (1895-1953).<sup>4</sup> Still, on the international stage, I have a great appreciation for the history of bioethics, in knowing who were the pioneers who started this field of study, what were the main problems faced and how they were solved, what documents were prepared to present the ethical guidelines that regulate scientific activity in this area and also the relationship between ethics and science.

This interest in the history of bioethics became even stronger from September 2018, when I joined the Research Ethics Committee, and recently from March 2020, when I joined the Animal Ethics Committee at the university where I work. It is clear that, from that moment on, my interest in bioethics had a focus on research ethics. This also made me want to learn about the development of research on applied ethics in Brazil and it was at this point that my interest in wanting to study the history of bioethics in Brazil began.

The history of the origin and evolution of bioethics – whether national or international – has been narrated in several books, chapters, essays and conferences. Most of these

2 From now on, all acronyms follow the names in Portuguese, and in some cases in Spanish.

3 See the following publications: (i) Zanella, Diego Carlos (2018), *Humanidades e ciência: uma leitura a partir da bioética de Van Rensselaer (V.R.) Potter*, *Interface (Botucatu)*, 22 (65), 473-480.; (ii) Pessini, Leo, Sganzerla, Anor and Zanella, Diego Carlos eds., (2018), *Van Rensselaer Potter: um bioeticista original*. São Paulo: Loyola.; (iii) Sganzerla, Anor and Zanella, Diego Carlos eds., (2020), *A bioética de V. R. Potter: 50 anos depois*. Curitiba: Pucpress.; (iv) Pessini, Leo (2018), *Global Bioethics at a Time of Uncertainty, Perplexity and Hope*, <https://www.camilliani.org/wp-content/uploads/2018/12/Global-Bioethics-EN.pdf> (accessed: 29 Dec 2020).; (v) Muzur, Amir and Rinčić, Iva (2019), *Van Rensselaer Potter and His Place in the History of Bioethics*, Wien; Lit Verlag.

4 See Rinčić, Iva and Muzur, Amir (2019), *Fritz Jahr and the Emergence of European Bioethics*, Wien; Lit Verlag.

reports share a common structure. In general, they tend to define the beginning of bioethics in terms of a crucial catalyst moment, and subsequently emphasize certain historical events, the advances in biomedical technology and the ethical problems that have shaped the area since then. Despite the considerable amount of attention that has been devoted to the history of bioethics, there are still some disagreements.

Since each author is documenting and analyzing events (not as an external observer, but as a historical actor), their personal experience and contributions to the field will shape the way they interpret their history.<sup>5</sup> Therefore, understanding how bioethics has emerged and developed in Brazil as an area of study and research, and finally how it became institutionalized requires its history to be considered an ongoing academic effort. This is the methodological perspective that I adopt in this article, that is, it is a reconstructive analysis of the trajectory of bioethics in Brazil from the reports published by the main Brazilian bioethicists to make evident the main characteristic of Brazilian bioethics.

## **Bioethics in Brazil: The Beginning**

Efforts to consolidate and expand bioethics have increased in Brazil, namely, since the 1990s.<sup>6</sup> These actions have occurred both in the university environment and in the public sphere. Some examples are: the growing inclusion of bioethics content or even a course of bioethics in the curricula of undergraduate and graduate courses in the country, the creation and maintenance of several research groups that address a number of bioethics themes, the composition of specific committees and commissions to deal with issues in their context of operation in the most varied institutions and finally, the establishment of public structures that receive and sustain the demands necessary for the adequate development of this field of scientific knowledge.<sup>7</sup>

In Brazil, three facts are very significant: i) the creation of a biannual journal, *Revista Bioética*, published by the Federal Council of Medicine (CFM) in 1993; ii) the creation of the Brazilian Society of Bioethics (SBB) in 1995 to bring together researchers and people from different academic areas interested in bioethics; and iii) the edition of Resolution N.º 196 of October 10, 1996, of the National Health Council, a department of the Ministry of Health, which created the Brazilian

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5 See Fox, Renée C. and Swazei, Judith P. (2008), *Observing Bioethics*, Oxford; Oxford University Press, p. 29-32.

6 See Diniz, Debora, Guilhem, Dirce Bellezi and Garrafa, Volnei (1999), Bioethics in Brazil, *Bioethics*, 13 (3-4), 224-248.

7 See Figueiredo, Antônio Macena and Garrafa, Volnei and Portillo, Jorge Alberto Cordón (2008), Ensino da bioética na área das ciências da saúde no Brasil: estudo de revisão sistemática, *Interthesis*, 5 (2), 47-72.

Research Ethics System, that is, the Research Ethics Committees and the National Research Ethics Commission.<sup>8</sup>

In the specific case of Brazil, bioethics is consolidated and legitimized by its interest in public health problems. This profile is accentuated by the country's historical and geographical contexts. These questions are largely focused on the identification and attempts to minimize the problems rooted in old social inequalities and their perspective of defending human rights. This historical process and the attempts to face serious social problems link a significant part of the publications of Brazilian bioethics with the Health Reform.<sup>9</sup>

Despite the growing scope of the themes of Brazilian bioethics, most of the published works deal with moral conflicts that refer to bioethical aspects of public health. In these publications, the priority given to the principle of justice can be identified in a clear link between ethics and politics. In addition to the links with the Sanitary Movement, other reasons are identified during this initial period of bioethics as being more focused on techniques rather than reflection. This type of bioethics "*made in Brazil*"<sup>10</sup> assumes for itself some of the demands of public health, such as the universalization of health services and the allocation of health resources, and incorporates other aspects related to the socioeconomic dimension and quality of life.

## Bioethics in Brazil: Maturation

Bioethics developed in Brazil in the 1990s. Gradually, it started to gain space and constituted itself in the country, where its first publications and institutional initiatives appeared, especially in universities. But, from a theoretical point of view, what was the main characteristic of bioethics produced in Brazil in this period of institutionalization? Ethical conflicts generated by new technologies constitute the central axis of bioethics in developed countries. The same can be said about the creation of the *Revista Bioética* in 1993 and the reformulation of the ethical guidelines for research involving human beings, which the country was going through in the 1990s, resulting in the Resolution N.º 196 of October 10, 1996, of the National Health Council.

8 See Diniz, D., Guilhem, D. B. and Garrafa, V. (1999), p. 246-247.

9 See Schramm, Fermin Rorand (2008), A identidade sanitária da bioética brasileira e a bioética da proteção no contexto da globalização. *Revista Facid: Ciência & Vida*, 4 (1), 129-142.; Porto, Dora and Garrafa, Volnei (2011), A influência da Reforma Sanitária na construção das bioéticas brasileiras, *Ciência e Saúde Coletiva*, 16 (1), 719-729.

10 Schramm, F. R. (2008), p. 129.

As bioethical concepts and procedures were established for research involving human beings, the country perfected a slowly unfolding process to regulate research and human participation in scientific studies. The limits of ethical regulations change when considering the local reality of each country, and in part, the differences among these regulations reflect most of the current experiences performed in each country. When analyzing the development of bioethics in the international scenario and the need for a regulatory system for bioethics in Brazil, taking into account aspects related to human experimentation, Marília Bernardes Marques states that:

new technologies have heightened controversies and conflicts of interest at the interfaces between science, government and private companies, which lead to discussions about national interests – a concept in itself limited in theory, in the study of international relations – characterized by arbitrariness.<sup>11</sup>

In the last decades, Brazil has been increasingly committed to the international agenda, thus intensifying, readjusting, or incorporating new issues in its agenda. However, what is the Brazilian agenda from which the national interest could be identified? The analysis of government plans of the last three decades, for example, could help in identifying the national interest since this is often indicated as a justification for the positions and policies adopted by States in the international sphere, even to cover up economic, ideological, educational sector interests, among others.

The fact is that this national agenda ends up influencing the national socio-cultural context. In the Brazilian case, the socio-cultural context, which consists of diversities that go beyond the territorial issue, was weakened in the 1990s and continues to be by the maintenance of structural inequalities.

The country had a long experience of colonialism and just over a hundred years ago it was still intensely experiencing slavery. The cultural balance of this heritage resulted in low self-esteem and a weakened concept of citizenship among people. Among the social prices of this process so far are, on the one hand, the *dependence* on other economically and politically more powerful countries; on the other hand, there are the enormous internal social inequalities that reproduce an exploratory and anti-solidarity spirit.<sup>12</sup>

In addition to this, there is another underlying element that needs to be highlighted, namely, the difficulty in consolidating citizenship and democracy in the country.

One of the most striking characteristics of the Brazilian State is precisely its authoritarianism. Historically, Brazilian society has profound elitist and exclusionary traits, partly a legacy of slavery from the colonial period and the oligarchic character

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11 Marques, Marília Bernardes (1996), A bioética na política pública do Brasil, *Revista Bioética*, 4 (2), 7.

12 Anjos, Márcio Fabri dos (2002a), Bioética no Brasil: algumas notas, in: Barchifontaine, Christian de Paul and Pessini, Leo eds., *Bioética: alguns desafios*, São Paulo, Loyola 2002, p. 67.

of the ruling classes. In this sense, the State imposed its dominance on society through the exercise of political patrimonialism, clientelism and the incorporation of the “subordinate” classes through co-optation mechanisms that guaranteed the supremacy of the elites in the exercise of politics.<sup>13</sup>

This characteristic of the Brazilian State has always been present in the political history of the Republicans in Brazil and has never been removed from Brazilian society. It is a problematic and persistent feature in the history of the country. However, the important thing here is to understand that these are structural inequalities and that they affect the country not only in the political and economic spheres but also socially and culturally. In this context, there seems to be a mentality that accompanies, cultivates, and is well accommodated with such inequalities and, precisely for this reason, one can speak of the difficulty in consolidating citizenship and democracy which have remained as “unfinished” tasks in the country.<sup>14</sup>

In Brazil, in this initial period of bioethical reflection, the scientific and intellectual production focused on concerns about the effects on human life with the excessive use of biomedical technology. These problems were a challenge for ethics in an attempt to provide a solution to such controversies arising from the biomedical sciences and high technologies applied to health. Joaquim Clotet, in an article published in the inaugural issue of *Revista Bioética*, presented some of these reasons that motivated bioethical reflection. He argued that the development of science had allowed the creation of new techniques for manipulating nature. The increasing use of these techniques has revealed a certain gap between the progress of technology and the maturation of moral reflections on its results.<sup>15</sup>

Brazilian society is being surprised by the media with new techniques of transmission and termination of life, and wonderful innovations in the treatment of some diseases. There is no doubt that the social impact is great, and it has repercussions in the family sphere, in the individual and collective conduct. It is a socio-cultural fact that affects humanity and causes perplexity, but also hope. While the *mass media* explore some of these themes, the medical class, which is the protagonist and the exceptional witness, has to take a stand on its way of acting and its responsibilities.<sup>16</sup>

Although these were the expectations of several Brazilian bioethicists, an article on the content of Brazilian publications on bioethics from 1982 to 1997, by Lorenzo & Azevêdo, showed that the theme of these articles focused primarily on the ethical

13 Gerschman, Silvia (2004), *A democracia inconclusa: um estudo da reforma sanitária brasileira*, Rio de Janeiro, Fiocruz, p. 31.

14 See Gerschman, S. (2004).

15 See Clotet, Joaquim (1993), Por que bioética? *Revista Bioética*, 1 (1), 13-19.

16 *Ibid*, p. 13.

conflict caused by the technical-scientific progress of modern medicine, leaving the factors of the country's social and economic reality in the background.

The majority of the country's publications were mainly from deontological and religious areas, with a small contribution from scientific institutions and medical scientific associations. Although Brazil has, in its main cities, a large number of services well equipped with the latest generation of biomedical technology, its poverty and inhumane medical public health care is considerably larger. Thus, its greater bioethical conflicts must be coming from the area that Berlinguer<sup>17</sup> designates as "Daily Bioethics", like malnutrition, illiteracy and deficient health care, for example. However, as the present results show, publications on bioethics in Brazil are yet to be identified with these problems.<sup>18</sup>

In the context under analysis, the main agent who fought against this characteristic and tried to reduce structural inequalities in the health area was the movement that became known as the Brazilian health reform,<sup>19</sup> i.e., a group of people who were directly involved in health and who used a medical-social framework in an attempt to transform health in Brazil. This movement, between achievements and failures, was largely responsible for the content of the chapter on health in the Federal Constitution of 1988, largely achieved at the 8<sup>th</sup> National Health Conference in 1986, two years before the promulgation of the constitution.

It is in this context that Brazilian bioethical production was gradually becoming familiar in the late 1990s. The article by Lorenzo & Azevêdo,<sup>20</sup> which mentions the Italian sanitary doctor Giovanni Berlinguer, very influential in the Brazilian health reform, and another text by Eliane S. Azevêdo in *Caderno Mais*, from *Folha de São Paulo*, already pointed out the social issues that should be a part of the bioethics discussion agenda.<sup>21</sup> According to Berlinguer, the second half of the twentieth century

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17 Giovanni Berlinguer (1924-2015) was an Italian sanitary doctor and the main intellectual mentor of the Brazilian health reform. *Daily bioethics* aims to "attract attention, which at the moment is concentrated almost exclusively in the extreme cases of intervention on life, that is, on what before the recent development of the biomedical sciences was impractical and, at times, even unthinkable [...] for the existence of another bioethics, closer to the experience of all people and every day" (Berlinguer, Giovanni (2004), *Bioética cotidiana*, Brasília; Editora UnB, p. 9-10).

18 Lorenzo, Claudio and Azevêdo, Eliane S. (1998), Bioethics publications in Brazil: A study of topic preferences and tendencies, *Eubios Journal of Asian and International Bioethics*, 8, 148-150.

19 "Health Reform can be understood as a process of establishing a 'partial democracy', or as a 'partial regime', in which its effective institution and institutionalization would update, in the political arena of health, the condition of the possibility of exercising citizenship [...]. In other words, the establishment of political institutions, periodic elections and political parties are not sufficient conditions for the consolidation of democracy: the issue of equity is the main issue for democracy to become effective" (Gerschman, S. (2004), p. 49).

20 See Lorenzo, C. and Azevêdo, E. S. (1998).

21 See Azevêdo, Elaine S. (1994), Debate sobre bioética deve abranger efeito da miséria, in: *Caderno Mais*, Folha de São Paulo, 16 de outubro.

was marked by a major scientific leap in the scope of biomedical sciences with rapid technological advancement.

Because of this, the author in question elaborated a critique of the pace of such an advance, which ends up contributing to a predominant tendency in the studies of the “limits and boundaries” of the sciences. This influential force leads to the neglect of important moral and scientific problems, which are present in the daily lives of thousands of people. In this and many ways, bioethics ends up privileging debates about extreme situations, such as euthanasia, organ transplantation, *in vitro* fertilization, etc., and forgetting to add, in the debate agendas, the basic health issues, for which “the title of nobility as an object of ethics is often denied and, at best, it is only assigned the value [...] of ‘social issue’”.<sup>22</sup>

In this sense, the author points to the need to develop a bioethical debate not only on the “limits and boundaries” of the sciences, but also on the persistent situations of daily life. According to Berlinguer, daily bioethics is ahead in discussions of frontier issues, such as life and death, which are important but are not the only guidelines. As a result, it is necessary to break the silence and uncertainty that influence issues of daily life and health and that dominate ethics concerning historically persistent themes.<sup>23</sup>

The direction pointed out by Berlinguer and other Brazilian authors were fundamental, since a significant part of the scholars who were dedicated to bioethics started to worry about issues related to the community, as quoted: “social inequalities, equity, demographic and population issues, individual and collective responsibility about health care, allocation of scarce resources, poverty, racism, public health and health policies and distributive justice”.<sup>24</sup>

These concerns with social issues can also be seen in the results of the aforementioned article by Lorenzo & Azevêdo, which investigated the preferences and trends of topics in bioethical publications in Brazil from 1982 to 1997. As a result, these authors report that:

- a) Among the 25 papers ascertained by the word “bioethics”, 16% gave great emphasis to the precarious health care in Brazil and 16% to its social, economic and cultural reality. 44% of these papers focus on advances in technology.

22 Berlinguer, Giovanni (1996), *Ética da saúde*, São Paulo; Hucitec, p. 16.

23 See Berlinguer, G. (2004); Berlinguer, G. (1996).

24 Fortes, Paulo Antônio de Carvalho and Zoboli, Elma Lourdes Campos Pavone (2003), *Bioética e saúde pública: entre o individual e o coletivo*, in: Fortes, Paulo Antônio de Carvalho and Zoboli, Elma Lourdes Campos Pavone eds., *Bioética e saúde pública*, São Paulo, Loyola 2003, p. 14.



- b) Among the 49 papers ascertained by the word “ethics” plus its second selection criteria, the precarious health care in Brazil was the major subset in 14% of them, and social, economic and cultural reality in 20%. The advances in technology were a major topic in 16%.
- c) The 77 papers in the *Revista Bioética* and *Revista Medicina* took the precarious health care and the social, economic and cultural reality as a major topic in 8% and 18%, respectively. 18% took advances in technology as a major topic. Philosophy and theology were a major topic in 31% and 9%, respectively.
- d) Finally, among the 29 papers published in *Cadernos de Bioética*, precarious health care and social, economic and cultural reality were a major topic in 21% and 28%, respectively. However, philosophy and theology topics were treated as a major subset in 44% and 52%, respectively.<sup>25</sup>

Based on these data, the same authors conclude that “the growing of bioethics in Brazil already reached [in the 1990s] a point of no return”.<sup>26</sup> Therefore, the social themes of bioethics were already on the discussion agenda. It was only a matter of time before these topics also became bioethical theories. In this sense, the “1990s was, therefore, a fundamental period for the consolidation of bioethics, with a large specialized bibliographic production in Brazil. On the other hand, the year 2002 represented the stage of maturation of national bioethics”.<sup>27</sup>

In 2002, Brazil hosted the 6<sup>th</sup> World Congress on Bioethics, which took place in Brasília, from October 30<sup>th</sup> to November 3<sup>rd</sup>, 2002. In addressing the theme *Bioethics, Power and Injustice*, this congress included,

at the heart of the international bioethical agenda, issues related to inequalities and social exclusion [...]. The debates and clashes that took place, developed at a high intellectual level, brought to light the need for bioethics to incorporate current political themes into its field of reflection and applied action, especially the acute social and economic discrepancies between rich and poor, between nations in the northern and southern hemispheres.<sup>28</sup>

Fundamentally, this congress received the novelty of bioethics elaborated in the Brazilian way which, by highlighting politics and confronting social inequalities and the problems that originated in these contexts, contributed to the development of a more “politicized” bioethics. Ethical problems arise not only from extraordinary technological advances, but also from the discrepancies found in access to health,

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25 Lorenzo, C. and Azevêdo, E. S. (1998).

26 Ibid.

27 Braga, K. S. and Diniz, D. (2002), p. 10.

28 Garrafa, Volnei and Pessini, Leo (2003), Apresentação, in: Garrafa, Volnei and Pessini, Leo eds., *Bioética: poder e injustiça*, São Paulo, Loyola 2003, p. 12-13.

education, food, housing, and transportation, for example. The inequalities and the inaccessibility to a dignified existence of the majority of the population worldwide, including Brazil, reveal a profound lack of ethics.

As noted, the development of bioethics has been driven by several ethical, medical, and technological problems that have drawn the attention of society. In many situations, the impulse resulted from the population's discontent concerning how medical technological advances were applied to human life.<sup>29</sup> Ethical conflicts generated by new technologies constitute a central axis of bioethics in developed as well as developing countries, as is the case in Brazil. However, there is an agreement among Brazilian authors on the need for emerging issues to be discussed and analyzed concerning the country's specific bioethical problems, always based on the social reality and the moral values of Brazilian society.<sup>30</sup> In this sense, the search for the construction of a "Brazilian bioethics" must be "able to face, mediate and, if possible, give answers to the moral conflicts emanating from the different bioethical questions related to the customs [...] in force in our society".<sup>31</sup>

In contrast to the main focus of Brazilian bioethical publications at the time, namely, the ethical conflict caused by the technical-scientific progress of modern medicine, Brazilian bioethics also sought its characteristics by dedicating itself to both persistent and emerging ethical problems. This was not, however, the dominant trend.

If from a structural point of view, bioethics in Brazil has been able to take its first steps, but unfortunately, the same is not true of work in bioethics theory. A good indicator of that is the fact that there are almost no books on bioethics edited in the country. Besides the few translations into Portuguese, existing Brazilian books are collected works where practically all the Brazilian bioethicists write a thematic chapter. Hence, the development of bioethics for us is characterized by the importation of bioethical theories and, as we have already said, basically by the adoption of the principlist theory. A few researchers try to escape the hegemonic character of the principlist theory but, as a general rule, the role of bioethicists is limited to replicating the instruments of the principlist theory.<sup>32</sup>

These early years of assimilation of imported bioethical ideas were important for the maturation of Brazilian bioethical issues that were beginning to emerge at the turn of the millennium. "The influence of the American hegemonic perspective throughout

29 See Clotet, Joaquim (2003), *Bioética: uma aproximação*, Porto Alegre; Edipucrs.

30 See Azevêdo, E. S. (1994).

31 Costa, Sérgio Ibiapina Ferreira and Garrafa, Volnei and Oselka, Gabriel (1998), Apresentando a bioética, in: Costa, Sérgio Ibiapina Ferreira and Garrafa, Volnei and Oselka, Gabriel eds. (1998), *Iniciação à bioética*, Brasília, Conselho Federal de Bioética 1998, p. 16.

32 Diniz, D., Guilhem, D. B. and Garrafa, V. (1999), p. 248.

the world at that time strongly conditioned the uncritical import of the principlist model of bioethics”.<sup>33</sup> In this sense, and following other international trends, some Brazilian bioethicists began to outline their criticisms of the dominant bioethical model, originated in the United States,<sup>34</sup> and build their bioethical theories.

## **Bioethics in Brazil: Lines of Thought**

As we have seen, bioethics arrived late in Brazil, i.e., in the early 1990s because “the country was [in previous years] under the military dictatorship, which explains why bioethics took considerably long to consolidate itself” in the country.<sup>35</sup> After its arrival, the country went through a period of assimilation of bioethical theories and remained under the influence of the American principlist model for more than a decade. As stated below,

The reductionism of bioethics to the biomedical field, contrary to the essential characteristic of this field, had serious implications since bioethics came to be seen almost as an attachment to the deontological codes, destined to regulate failures, to arbitrate about ethical conflicts, to minimize the damages of research and the ethical application of biosciences and biotechnology.<sup>36</sup>

This context, little by little, was proving uncomfortable to many Brazilian bioethicists, who began to elaborate their proposals to better understand and resolve the moral conflicts of Brazilian (and also, Latin American) society. In this set of texts and theories, “what exists is a set of references and authors, constituting a rich mosaic that represents the brilliance and success of bioethical research in Brazil”.<sup>37</sup>

To organize this mosaic of theoretical positions, I will refer primarily to three theoretical concepts that are genuinely Brazilian and that are closest to the country’s social reality, although I know that there are other lines of bioethical thought practiced in Brazil that have been influenced by international perspectives. The three theoretical concepts are: i) *Bioethics of Protection*; ii) *Bioethics of Intervention*; and iii) *Bioethics and Liberation Theology*.

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33 Porto, D. and Garrafa, V. (2011), p. 723.

34 See Diniz, D., Guilhem, D. B. and Garrafa, V. (1999); Garrafa, Volnei, Martorell, Leandro Bambrilla and Nascimento, Wanderson Flor do (2016), *Críticas ao principlismo em bioética: perspectivas desde o norte e desde o sul*, *Saúde e Sociedade*, 25 (2), 442-451.

35 Porto, D. and Garrafa, V. (2011), p. 722.

36 Siqueira, José Eduardo de and Porto, Dora and Fortes, Paulo Antonio de Carvalho (2007), *Linhas temáticas da bioética no Brasil*, in: Anjos, Márcio Fabri dos and Siqueira, José Eduardo de eds. (2007), *Bioética no Brasil: tendências e perspectivas*, Aparecida, Ideias & Letras 2007, p. 162.

37 Braga, K. S. and Diniz, D. (2002), p. 14.

*Bioethics of Protection* is defended and developed especially by Fermin Roland Schramm, a professor at the National School of Public Health of the Oswaldo Cruz Foundation (FIOCRUZ), and also by Miguel Kottow, a Chilean professor from the School of Public Health, University of Chile. Both authors began their reflections on Bioethics of Protection in an article that had the following question as a fundamental problem: “Has bioethics developed the right tools to face the main moral dilemmas that occur in public health programs and practices?”<sup>38</sup> In this text, the authors point out some limitations and trends when considering this issue. They report that most authors tend to adopt the conceptual instruments of clinical bioethics to individualized contexts and the four-principled model to collective public health contexts. As these strategies encounter many difficulties, the authors decided to explore possible ethics for public health, that is, more attentive to the moral conflicts in this area, which was later designated as *Bioethics of Protection*.

Bioethics of Protection was developed for two main reasons. First, to rethink a tool that is theoretically and practically effective in the context of a credibility crisis that affects the field of global bioethics, faced with moral conflicts that cannot be resolved with their tools, which, on the one hand, intend to have a universal value, but which, on the other hand, are not universal, since they are thought and applied without taking into account the specificity of concrete situations, that is, their *différance*. Second, to deal with a situation of particular moral conflict, such as that represented by the health and quality of life of the majority of Latin American and Caribbean populations and, probably, those who are in similar situations also in this way called “underdeveloped world”.<sup>39</sup>

In this sense, Bioethics of Protection is seen as an ethical reflection on health justice in situations of a scarcity of resources. This proposal comprises a set of peculiar attitudes and devices that are used by the community to challenge the main public health problems, whether collective or individual. For this reason, Bioethics of Protection is configured as a way of thinking about public health based on “the application and adaptation of traditional bioethical knowledge tools to moral conflicts and dilemmas”<sup>40</sup> that are typical of public health.

*Bioethics of Intervention* was developed and defended by students and researchers along with Volnei Garrafa and Dora Porto, who coordinated the UNESCO Chair in Bioethics at the University of Brasília (UnB), where both founders of this Brazilian

38 Schramm, Fermin Rorand and Kottow, Miguel (2001), Principios bioéticos en salud pública: limitaciones y propuestas, *Cadernos de Saúde Pública*, 17 (4), 950.

39 Schramm, Fermin Rorand (2006), Bioética sem universalidade? Justificação de uma bioética latino-americana e caribenha de proteção, in: Garrafa, Volnei and Kottow, Miguel and Saada, Alya eds., *Bases conceituais da bioética: enfoque latino-americano*, São Paulo, Gaia 2006, p. 145-146.

40 Schramm, Fermin Rorand (2017), A bioética de proteção: uma ferramenta para a avaliação das práticas sanitárias? *Ciência & Saúde Coletiva*, 22 (5), 1533.

theory of bioethics currently work. Intervention Bioethics – originally called *strong bioethics* or *hard bioethics*<sup>41</sup> – began to be conceived in the late 1990s, but it was only in the early 2000s that it was officially formulated. The starting point of these authors was the questioning that bioethics, developed in its places of creation – in the United States, by Van Rensselaer Potter (1911-2001) and the Kennedy Institute of Ethics, and in Germany and Europe, by Fritz Jahr (1895-1953) –, did not take into account the situation of the excluded and marginalized who do not have (or have little) access to rights and goods that can guarantee a dignified existence.<sup>42</sup>

As a result, the authors of this bioethical concept felt the need to elaborate a bioethical reflection towards the Brazilian reality. This reflection intends to be operationalized in an appropriate way to find possible solutions to the obstacles that hinder or prevent the existence of a more just society. Therefore, the authors started to use their nomenclature to deal with moral conflicts. Bioethical problems are classified as emergent and persistent situations. The bioethics of emerging situations is concerned with issues arising from scientific and technological development that have emerged in recent decades, such as new reproductive techniques, advances in the field of genetic engineering, human organ, and tissue transplants, among others. On the other hand, the bioethics of persistent situations deals with those historically unsolved problems in human societies, for example, social exclusion, poverty and different forms of discrimination.<sup>43</sup> While emerging problems have a high cost from a financial point of view, persistent problems, on the other hand, have a high cost from a human point of view, as they impede the development of a dignified existence and are postponed by compensatory measures.

In addition to these two concepts, the authors also use two others. Non-peripheral countries are all those in which the basic problems of health, education, food, housing, and transport, for example, are already properly resolved or with solutions in place. The peripheral countries, in turn, are all nations in which the majority of the population still struggles for minimum conditions of survival with dignity and where the concentration of power and income is in the hands of a small number of people.<sup>44</sup> That is, while the non-peripheral countries enjoy a comfortable situation because they present only a portion of the emerging situations, the peripheral countries still need to resolve their persistent problems and, of course, to debate on emerging issues.

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41 See Garrafa, Volnei and Porto, Dora (2008), *Bioética de intervención*, in: Tealdi, Juan Carlos ed. (2008), *Diccionario latinoamericano de bioética*, Bogotá, Red Latinoamericana y del Caribe de Bioética (UNESCO) y Universidad Nacional de Colombia, p. 161.

42 See Garrafa, Volnei and Porto, Dora (2003b), *Intervention Bioethics: a proposal for peripheral countries in a context of power and injustice*, *Bioethics*, 17 (5-6), 399-416.

43 See Garrafa, Volnei and Porto, Dora (2003a), *Bioética, poder e injustiça: por uma ética de intervenção*, in: Garrafa, Volnei and Pessini, Leo eds., *Bioética: poder e injustiça*, São Paulo, Loyola 2003, p. 36.

44 See Garrafa, V. and Porto, D. (2003a), p. 36.

The inequality that marks the relations between peripheral and non-peripheral countries and between the rich and poor segments of their populations makes existence a pleasure for a few, revealing suffering to millions of people. The obscurity of such a prognosis can only be overcome when nation-states act resolutely, intervening for the concrete benefit of their populations. And when they, awakening from the narcotizing sleep sponsored by the unilateralism of the consumer society, emancipate themselves from oppression and take the defense of their own lives and the future of the planet in their hands.<sup>45</sup>

Thus, according to these authors, bioethical debates arise to collaborate in the search for balanced responses to existing and future problems. Once the idea of the neutrality of science has been overcome, bioethical approaches need to be plural and involve other disciplinary knowledge to produce more complete views of concrete reality.<sup>46</sup> In this sense, and putting into perspective the reality of developing countries, the simple uncritical acceptance of bioethical theories originated in developed countries is no longer sufficient, in which discussions mainly surround themes related to the boundary or border situations that result from scientific and technological development. Based on this, Garrafa & Porto suggest that developing countries “should preferably be concerned with persistent situations”,<sup>47</sup> assuming the commitment to take advantage of the scope and opportunity that bioethics provides, as it tries to study the ethics of life situations in a broad sense.

*Bioethics and Theology of Liberation* are defended and developed mainly by the theologian and Redemptorist priest Márcio Fabri dos Anjos. This line of bioethical thinking presents itself as a genuine discourse in moral discussions in defending the need to embrace moral pluralism in bioethics. This perspective also presents bioethics as a bridge between science and religion and a channel of respectful and enriching dialogue. Liberation Theology – a line of theological thought in Latin America that defends the premise that the Gospel requires the preferential option for the poor – has influenced many Brazilian thinkers.<sup>48</sup> Liberation Theology was conceived within the suffering Latin American continent and has its attention turned to the suffering of the excluded and socially marginalized. Hence, when making its preferential option for the poor, it is totally coherent with the Christian faith.

45 Porto, Dora and Garrafa, Volnei (2005), Bioética de intervenção: considerações sobre a economia de mercado, *Revista Bioética*, 13 (1), 121.

46 See Garrafa, Volnei (2006), Multi-inter-transdisciplinaridade, complexidade e totalidade concreta em bioética, in: Garrafa, Volnei and Kottow, Miguel and Saada, Alya eds., *Bases conceituais da bioética: enfoque latino-americano*, São Paulo, Gaia 2006, p. 73-86.

47 Garrafa, V. and Porto, D. (2003a), p. 35.

48 See Anjos, Márcio Fabri dos (2008), Teología de la liberación, in: Tealdi, Juan Carlos ed. (2008), *Diccionario latinoamericano de bioética*, Bogotá, Red Latinoamericana y del Caribe de Bioética (UNESCO) y Universidad Nacional de Colombia 2008, p. 12-14.

In addition, it resolutely defends the dignity of the poor and the vulnerable and does not do so guided by abstract propositions, but by pointing out those responsible for social problems and identifying paths to liberation. On this premise, a bioethical thought also started to be developed from this focus. The relationship between Bioethics and Liberation Theology is based on the idea of God as the great Creator of the world and the idea of human beings as co-creators and responsible for their conduct to a full life.<sup>49</sup> Therefore, this line of thought bases its bioethical reflection on three interrelated dimensions, defined as micro, midi, and macro.<sup>50</sup>

The bioethical thinking of Liberation Theology has a peculiar view that Brazil and the other Latin American countries are fertile lands due to the social inequalities that exist in these countries. Therefore, its main focus is on the poor, that is, the most vulnerable people in society. Because it was one of the first bioethical theories developed in Latin America to draw attention to the need for articulation with the social dimension, this line of thought is deeply committed to social justice.<sup>51</sup>

The relationship between Bioethics and Liberation Theology collaborates with bioethical reflection in these three areas: i) the specificity of ethical reflection (ethics); ii) the conception of a human being underlying biotechnological interventions (anthropology); and iii) the way human beings relate to nature (ecology).<sup>52</sup> In this line of thought, there is a “mystique” for bioethics, which is understood as “the set of hidden and underlying forces and motivations which combine their options and their criteria for the construction of the meaning and interpretation of life”.<sup>53</sup>

This mystique can also be understood as the ideals, utopian projections, or hopes of theorists. The advances in science and technology and their reflexes in contemporary society are also concerns of this bioethical perspective, based on new interpretations of meanings and in the sense of life itself, in addition to the relationship between human beings and each other and the environment. In this line of ideas, for theologians, unlike what happens with most scholars dedicated to other areas of knowledge, bioethicists are touched by a special sense of justice, solidarity, and humanism.<sup>54</sup>

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49 See Anjos, Márcio Fabri dos (2003), *Bioética em perspectiva de libertação*, in: Garrafa, Volnei and Pessini, Leo eds., *Bioética: poder e injustiça*. São Paulo, Loyola 2003, p. 455-465.

50 See Anjos, Márcio Fabri dos (2000), *Bioética nas desigualdades sociais*, in: Garrafa, Volnei and Costa, Sérgio Ibiapina Ferreira eds., *A bioética no século XXI*, Brasília, Editora UnB 2000, p. 53.

51 See Anjos, M. F. (2003).

52 See Anjos, Márcio Fabri dos (2002b), *Bioética: abrangência e dinamismo*, in: Barchifontaine, Christian de Paul and Pessini, Leo eds., *Bioética: alguns desafios*, São Paulo, Loyola 2002, 17-34.

53 Anjos, M. F. (2000), p. 54.

54 See Anjos, M. F. (2003).

## Conclusions

To reassemble the context of the arrival, development, and foundation of bioethics in Brazil is to build a “mosaic”<sup>55</sup> of this history, showing what the “initiatives”<sup>56</sup> that constituted bioethics in Brazil were. This historical journey went through some phases, from assimilation through appropriation to maturity, which color, beautify and ornament Brazilian bioethics.

The study carried out was defined by the search for understanding the development and foundation of bioethics in Brazil. With this in mind, I sought to analyze these constitutive moments from the initial context to the maturation of Brazilian bioethics. The background is the trajectory of struggles and conquests from the classes of various professionals in defense of citizen’s rights. When drawing a retrospective study of the emergence of bioethics in Brazil, it is essential to recognize that it goes far beyond its nomenclature. A simple neologism in its conjecture, a knowledge that aims to study the most varied ethical relationships in life, becomes the center of a complex network around the reflection on values, clinical practice, and attitudes towards life.

Although one may have encountered inaccuracies, which result from the limitation of material, the scarcity of sources, or the lack of documentation on the history of bioethics in Brazil, I sought to gather data to highlight the fundamental social character of Brazilian bioethics. It covers transdisciplinary themes, conquering the primary space within the scope of human and social formation. This characteristic highlights a concern of the majority of Brazilian bioethicists with Brazilian society itself, that is, a concern with the everlasting problems of Brazil which are never resolved, such as poverty, social inequality, vulnerability, and injustice, among others. These issues started to become increasingly present in the country’s bioethical productions and also in normative documents.

Thus, it can be seen that the trajectory of bioethics in the country is supportive of social expectations, and the constant challenges are related to the difficulty of effectively meeting collective interests, creating an action within the fight against inequalities in search for democratic legitimacy. To overcome these obstacles, mechanisms for the inclusion of bioethical discussions are necessary for the spaces in which the directions of public policies are defined. Besides, it is only through the expansion of these spaces for concrete interventions that it will be possible to transform the reality of citizens and resolve ethical conflicts related to health and adverse situations arising

55 Braga, K. S. and Diniz, D. (2002), p. 14.

56 Hossne, William Saad, Albuquerque, Maria Clara and Goldim, José Roberto (2007), Nascimento e desenvolvimento da bioética no Brasil, in: Anjos, Márcio Fabri dos and Siqueira, José Eduardo de eds., *Bioética no Brasil: tendências e perspectivas*, Aparecida, Ideias & Letras 2007, 144.



from technological advances, shedding light on emerging and persistent themes in peripheral and non-peripheral countries as well.

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# Je li brazilska bioetika socijalna bioetika? Osobna procjena

## SAŽETAK

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Rad ima za cilj predstaviti okolnosti u kojima je utemeljena bioetika u Brazilu. U tu svrhu provest će se opisna i dokumentarna istraživanja nastanka bioetike kao polja istraživanja i procesa njene institucionalizacije u Brazilu. U tom smislu tri su činjenice vrlo značajne: i) pokretanje časopisa *Revista Bioética* 1993. godine, koji izdaje Savezno vijeće za medicinu (izlazi dvaput godišnje); ii) stvaranje Brazilskog društva za bioetiku 1995. godine, koje će okupiti istraživače i ljude iz različitih akademskih područja zainteresiranih za bioetiku; i iii) donošenje Rezolucije br. 196 od 10. listopada 1996. Nacionalnog zdravstvenog vijeća, koja je stvorila brazilski sustav istraživačke etike, odnosno Odbor za istraživačku etiku i Nacionalno povjerenstvo za etiku istraživanja. Te će tri činjenice omogućiti prepoznavanje glavnih elemenata brazilske bioetike i formiranje njenih prvih teorijskih modela. Ovo će istraživanje, stoga, donijeti pregled brazilske bioetike, u kojem će se prepoznati karakteristični akcenti brazilske bioetičke misli.

**Ključne riječi:** brazilska bioetika, povijest bioetike, ranjivost, socijalna bioetika.