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Ribeiro Parizi Carvalho, Regina; Zafalon Martins, Gerson; Bartolomeu Greco, Dirceu
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The Brazilian Society for Bioethics: a bioethics of commitments

Regina Ribeiro Parizi Carvalho¹, Gerson Zafalon Martins², Dirceu Bartolomeu Greco³

Abstract

In order to document two consecutive terms leading the Sociedade Brasileira de Bioética (the Brazilian Society for Bioethics), the authors provide a retrospect of Brazilian bioethics since the inception of the SBB, including the establishment of dedicated ethical journals, national and international events, and of academic programs aimed at qualifying professionals in multidisciplinary fields and to disseminate this knowledge among Brazilian, Latin-American and Lusophone societies. They emphasize that since the beginning of the bioethical debate in Brazil there has been a clear focus on human rights protection. During the current board's term, challenges have included population aging in Brazil; the impact of emerging/reemerging illnesses; the increase of urbanization; the impact of technological progress; pressures to lower ethical requirements for human research; economic and communication globalization. This has come amid a severe international economic and political crisis, culminating in Brazil with the impeachment of an elected president and with the succeeding government proposing privatizations and reforms that will negatively affect workers' rights. All these points set the agenda for the new term of office.

Keywords: Bioethics-Brazil-Human rights. Decision-Conscience-Information. Social responsibility-Education-Citizen participation.

Resumo

Sociedade Brasileira de Bioética: uma bioética de compromissos

Para documentar dois mandatos à frente da Sociedade Brasileira de Bioética, os autores fazem retrospectiva da disciplina no país, com a criação da entidade associativa, de revistas científicas, eventos nacionais e internacionais, bem como programas acadêmicos para formação em campos multidisciplinares e divulgar a bioética para a sociedade brasileira, latino-americana e lusófona. Ressalta que desde o início dos debates a bioética brasileira teve sua atuação relacionada estreitamente com a defesa dos direitos humanos. No período de gestão os desafios se relacionavam ao envelhecimento populacional, ao impacto de doenças emergentes/reemergentes, ao aumento da urbanização, ao crescimento da tecnologia, às pressões para diminuir os requisitos éticos para pesquisas envolvendo seres humanos, globalização da economia e da comunicação; somados à grave crise econômica e política internacional, que no Brasil culminou com o impeachment da presidente eleita e reformas privatistas que subtraem direitos dos trabalhadores. Isto tudo determina a pauta para o novo mandato.

Palavras-chave: Bioética-Brasil-Direitos humanos. Decisões-Consciência-Informação. Responsabilidade Social-Educação-Participação cidadã.

Resumen

Sociedad Brasileña de Bioética: una bioética de compromisos

Para documentar dos mandatos al frente de la Sociedade Brasileira de Bioética (Sociedad Brasileña de Bioética), los autores ofrecen una retrospectiva de la disciplina en el país, con la creación de la entidad asociativa, de revistas científicas, de eventos nacionales e internacionales, así como de programas académicos para la formación en campos multidisciplinarios y para difundir la bioética en la sociedad brasileña, en Latinoamérica y en los países lusófonos. Se destaca que desde el inicio de los debates, la actuación de la bioética brasileña estuvo estrechamente relacionada con la defensa de los derechos humanos. En el período de gestión, los desafíos se relacionaban con el envejecimiento poblacional, el impacto de las enfermedades emergentes/reemergentes, el aumento de la urbanización, el crecimiento de la tecnología, las presiones para reducir los requisitos éticos para la investigación con seres humanos, la globalización de la economía y de las comunicaciones; sumados a la grave crisis económica y política internacional, que en Brasil culminó con el *impeachment* de una presidente electa y con reformas privatistas que afectan a los derechos de los trabajadores. En suma, todo esto determina la agenda para el nuevo mandato.

Palabras clave: Bioética-Brasil-Derechos humanos. Decisiones-Conciencia-Información. Responsabilidad social-Educación-Participación ciudadana.

1. **Doutora** pariziregina@gmail.com – Centro de Estudos e Pesquisa (Cedep/lamspe), São Paulo/SP 2. **Doutor** gerson@portalmedico.org.br – médico perito judicial, Curitiba/PR 3. **Doutor** dirceugreco@gmail.com – Universidade Federal de Minas Gerais (UFMG), Belo Horizonte/MG, Brasil.

Correspondência

Regina Ribeiro Parizi Carvalho – Rua Dr. Diogo de Faria, 1.311, apt. 51, Vila Clementino CEP 04037-005. São Paulo/SP, Brasil.

Declararam não haver conflito de interesse.

Bioethics: a brief history

Although a relatively new area for the country, bioethics in Brazil soon became nationally and internationally relevant through the emergence of journals, representative entities, specialization and postgraduate programs, and the staging of events¹. In the nineteen nineties and the first decade of this century the dissemination of Brazilian bioethics was effervescent in the form of both debates and epistemological foundations, bringing new approaches to the ethical and moral values of a society that had remained under a military dictatorship for twenty years². This era also saw the construction of a universal health system, which was approved under the new Constitution³.

From the outset, one of the main points of debate in Brazilian bioethics was the discussion of principles and values that would not be restricted to the sphere of conflicts and dilemmas involving clinical practice and medical research, as was being proposed elsewhere, notably in the United States⁴. It was felt that bioethics, as conceived by Potter⁵ in "Bioethics: Bridge to the Future," should have global concern and reach, actively participating in the struggle for dignified conditions for all human beings on the planet.

Brazil, despite having the status of a "developing" country, remained among those nations with many socioeconomic inequalities and precarious indicators in the area of health. This led to many debates about the living and health conditions of the population, with the formulation of new theoretical perspectives on moral principles and the values that should prevail in policies and programs, especially in relation to health, education, gender equality, skin color and sexuality, among others.

The principles of election, as well as the application of these values, would come to determine specific ways of providing dignified living conditions for individuals, such as bioethics of protection, which advocates an ethical minimum to guarantee adequate living conditions for those who are vulnerable and fragile⁶. In another sphere, intervention bioethics points to the global and plural need to address persistent or emerging bioethical and moral issues in the concrete reality of the lives of individuals, collectivities and countries. Its aim is to seek solutions to conflicts from the perspective of equity, justice and universal human rights⁷.

Added to this is the need for the emancipation of people, as Freire advocates. Therefore, instead of "empowerment," one can also seek a bioethics of emancipation, in the sense attributed by Paulo Freire, who used the word with a broad sense of liberation and autonomy, exactly as it should be employed when fighting for citizenship, rights and against disparities⁸.

This emancipation will not occur through itself alone, nor will it be merely granted. Instead it will be earned by human praxis, which demands unceasing struggle. According to Freire, *liberation, therefore, is like childbirth (...)* Man born from this birth is new, and is only viable in and by overcoming the oppressed-oppressor contradiction, through the liberation of everyone⁹.

These debates had major repercussions, as the conflicts over persistent questions were added to emerging problems, intensified by the globalization of the economy, with the expansion of areas of communication and transport, from the second half of the 20th century¹⁰ onwards. In addition, major challenges related to rapidly spreading diseases and issues connected with the development of biotechnologies and population aging have arisen in the area of health^{11,12}.

From an ethical point of view, neoliberalism has brought new moral challenges to globalization, notably at the end of the century, creating a complex, plural and diverse world, accentuated by proposals of deregulation, a decrease in the presence of the State, increased concentration of wealth and deepening global inequalities¹³.

The 6th World Congress of Bioethics¹⁴, held in Brasília in 2002, contemplated most of these debates when dealing with issues of power and (in) justice. These discussions, in turn, were important precursors in the reasoning behind the *Universal Declaration on Bioethics and Human Rights*¹⁵, approved by the United Nations Organization for Education, Science and Culture (Unesco) in 2005.

During this period, Brazilian bioethics not only became established but also expanded into regulatory spaces, various areas of academic life and service industry, and in the administrative and legal sectors of the country. Authors and professors from different disciplines, as well as journalists, lawyers, religious figures and professionals from a variety of areas began to discuss and publish analyzes of clinical cases, moral dilemmas and social issues, grounding debates about conflicts and the dilemmas of life in society within bioethics.

Brazilian Society and Bioethics: mission and national context

When taking office in 2013, almost twenty years after the founding of the Sociedade Brasileira de Bioética - SBB (the Brazilian Society for Bioethics) in 1995, the current board realized that its mission, in addition to having grown, had become more complex. In considering the contributions of the last two decades, it was vital to take into account the contemporary scenario, a world troubled by armed conflicts, massive intercontinental migrations caused by wars and natural disasters, and increased poverty, among other issues. All this ended up accentuating disparity, gender inequality and the reappearance and emergence of epidemics¹².

On the other hand, new ethical and moral challenges had resurfaced with neoliberalism, especially the evident individualism in the way of seeing and thinking about life in society. This fact was observed during the economic crisis triggered by the banks in North America and Europe from 2008 onwards. The answer formulated by the financial sectors to face the crisis was to emphasize deregulation and diminish the participation of the State in the financing of social areas such as health, sanitation and education.

It is in this troubled world that we find the extensive, diversified and hypertrophied network of communication made possible by the internet, which, on one hand has revolutionized access to information and the exchange of ideas, but on the other has created new dilemmas related to confidentiality and privacy. It is worth mentioning the recent events involving the death of Marisa Letícia Lula da Silva, the former first lady of the country, which became a sad example of breaching the right to privacy and disrespect for the patient¹⁶. In general, the neoliberal project provoked significant behavioral changes, increased individualism and conservatism, while also exposing further the different interests of society¹⁷.

In Brazil, both bioethics and the SBB have expanded in this period, playing a strategic role in regulating and disseminating ethics committees in human research, broadening debate in the area of clinical bioethics and creating structural conditions for the training of personnel and multidisciplinary academic programs. There has also been significant Brazilian participation abroad, including through multilateral entities and intercontinental partnerships, which has helped spread bioethics

in Portuguese-speaking countries and in Latin America^{18,19}.

Brazil also experienced a period of economic growth with a more equal distribution of income in the first decade of this century, establishing itself as one of the few emerging countries that managed to reduce poverty and improve indicators of hunger and health, including the introduction of inclusive public policies of gender and race, among other areas²⁰. However, in 2013 notable signs of the economic crisis that had been spreading from the rich countries since 2008 could be seen, triggering heated debates on economic models and government policies involving society as a whole²¹.

The SBB, in turn, faced urgent challenges to not only maintain but to expand its activities in the face of this complex picture. Thus, in 2013, at the X Brazilian Congress of Bioethics in Florianópolis, Santa Catarina, there were immediate tasks to be dealt with such as the restructuring of the entity and the maintenance of ethical standards in research involving human beings. Exemplifying these conflicts was the controversy related to the revocation of CNS Resolution 196/1996, which regulated the presentation and monitoring of research projects in Brazil, and was replaced by the new Resolution CNS 466/12^{22,23}. Another important issue in the SBB agenda was the creation of the Comissão Nacional de Bioética (the National Bioethics Commission), directly linked to the Presidency of the Republic. The 3,497/2004 bill is still pending in Congress and maintains an urgent status while awaiting a plenary vote²⁴.

Other issues were included in the bioethical debate in subsequent years. Notable among these is the debate on the regulation of clinical research in Brazil, which gained greater significance with a bill in the Senate (PLS 200/2015), which proposes to eliminate or diminish several of the achievements achieved through the Comitês de Ética em Pesquisa - CEP (Research Ethics Committee) system and the Comissão Nacional de Ética em Pesquisa - Conep (the National Commission for Research Ethics) in 1996. Among these proposals is the extinction of Conep and the consequent end of the social control exercised by the Conselho Nacional de Saúde - CNS (National Health Council), authorization to use placebos even when there is an effective comparator available, and the significant decrease in post-study access to drugs that have been found more effective in research²⁵.

This has been an arduous struggle. On one side are the different entities that defend the safety

and rights of research participants and on the other are certain researchers, associated with sectors of the pharmaceutical industry, who propose the deregulation of what they call “bureaucracy.” Many feel that this would lead to a return to the conditions in research with human beings of the 1980s, when there were a number of accusations regarding technical and ethical questions related to research carried out in Brazil.

Despite representing a backwards step in terms of guarantees for the participants of clinical trials, this bill was passed in the Senate, with small and insufficient modifications on the use of placebos and the granting of post-research treatment. In addition, the suppression of the CEP/Conep system has continued and the system has been transferred to one of the secretariats of the Ministry of Health. After excluding important rights, the project is currently passing through Chamber of Deputies in 2017 under the denomination PL 7.082/2017²⁶. Of course, this will require a great deal of struggle in the next few years, so that the interests of big business, particularly from the pharmaceutical industry, one of the most profitable sectors of the world, can be challenged¹³.

Meanwhile, other subjects have been included in the bioethical agenda, such as emerging and reemerging viruses, as the number of cases of dengue, zika, chikungunya and yellow fever have increased. In relation to the zika virus, the right of women to interrupt pregnancy due to fetal malformation has been discussed, with the issue almost causing a diplomatic crisis when a group of international researchers proposed that Brazil postpone the Rio 2016 Olympic Games. SBB made a strong and evidence-based statement against this proposal²⁷.

Other pressing bioethical themes are population aging and the process of urbanization of society, advances in biotechnology with repercussions for the extension of life, organ transplants, the genome project, the use of transgenics, human enhancements and debates on autonomy, especially those related to advance healthcare directives²⁸.

In addition, there are the effects of neoliberalism on growing issues related to confidentiality and the use of the internet. And as a backdrop, there is the deepening economic crisis and the increasing global concentration of wealth and inequality, which has generated more conflicts and setbacks regarding equitable and human rights policies^{12,13}.

It was in this context of crisis and the intensification of ethical and moral debates on societal projects that the majority of SBB's board was reappointed for the 2015-2017 term. During this period the structural conditions of SBB improved, but its agenda remained practically subordinate to the economic crisis and the political and institutional chaos afflicting the country.

This situation was aggravated by the impeachment of president Dilma Rousseff, which politically radicalized and divided the main debates in Brazil, making it difficult to obtain the distance and impartiality necessary for the search for reliable information and for fair and equitable solutions. While part of the media moved its focus from major national problems and concentrated only on corruption, other important issues gradually emerged, even if in a timid manner, such as the risks of the neoliberal privatization project adopted by vice-president Michel Temer³⁰.

Brazilian society was initially paralyzed by the discourse of economic crisis and the need for financial austerity measures. But it has gradually begun to react against proposals that advocate budget cuts in the areas of health, education and sanitation, as well as the loss of labor rights through social security reforms.

Faced with the above, part of the population has begun to realize that the central values of the new proposals related to an expansion of the neoliberal project, with an increase of measures of deregulation, the privatization of institutions and outsourcing in the area of human resources. Fiscal adjustment, which will mainly affect the most vulnerable population, did not even discuss the urgent need to renegotiate the Brazilian public debt, a situation that benefits only banks and rentiers and consumes the funds allocated to social areas^{31,32}.

Throughout its mandate, the SBB board has tried to remain apart from party politics and focused on the ethical and/or bioethical analyzes of government policies introduced in Brazil. Thus, in addition to the aforementioned proposals that affect labor rights and weaken living conditions, other situations, involving clinical, health and professional conditions, have interspersed this scenario of prejudice and partisanship.

Among the major public health problems that have intensified in this period - and which will tend to worsen with the underfunding of the Unified Health System (SUS) and the approved proposals for the spending ceiling that will affect these areas³³ - it

is important not to forget the epidemics transmitted by *Aedes aegypti*, which may include extremely severe and complex cases such as Guillain-Barré syndrome or microcephaly.

Final considerations

The SBB plays a key role in protecting human rights and human dignity. This mission keeps the organization in a state of constant debate, positioning itself and disseminating its point of view in defense of citizenship. In addition, SBB will work further with social movements and representative councils in the areas of health, education and class, to change the situation of inequity, discrimination

and violence of gender, race and sexual orientation, among other issues. It is imperative that the society also addresses problems arising from population aging and the epidemiological transition that will intensify in the coming years.

It is essential that a firm and clear stance is maintained to establish sexual and reproductive rights and to ensure a transparent discussion on sexuality, diversity and violence at different levels of education. The SBB, together with the National Health Council, civil society and other entities, will continue to position itself in favor of maintaining the CEP/Conep system and against the proposed modifications in the regulation of clinical research in Brazil that diminish the rights of participants.

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Participation of the authors

All authors contributed to the article.

