

RELAÇÕES INTERNACIONAIS NO MUNDO ATUAL

CENTRO UNIVERSITÁRIO CURITIBA - UNICURITIBA - VOLUME 6 - NÚMERO 39/2023 I e-6296 I JAN-MARÇO I CURITIBA/PARANÁ/BRASIL - PÁGINAS 1 A 11 - ISSN: 2316-2880

BIOLAW, HUMAN RIGHTS AND BIOETHICS: NEEDS AND CHALLENGES IN THE CONTEMPORARY CONTEXTA

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ABSTRACT

Increasingly and with greater frequency, issues related to the biolegal order are being heard before the courts of justice; a fact that requires a high degree of scientific, ethical and legal knowledge. For this reason, the present work is framed in the discursive development and elements of comparative legal methods to deal with the similarities and controversies arising in the field of biolaw and bioethics in order to delimit the field of action and scope. The analysis of biolaw is assumed from the juridical model and its nexus with human rights. The rationality of current scientific-technical contributions, whose contributions are transcendental, is also discussed. Within the applicability, the discourse is extended on a critical issue such as the right to a dignified death or the power to extend life, where different positions in favor and against are exposed, recognizing the importance of the recognition of bio-rights.

Keywords: Biolaw; Human Rights; Bioethics; Dystanasia.





BIOLAW, DIREITOS HUMANOS E BIOÉTICA: NECESSIDADES E DESAFIOS NO CONTEXTO CONTEMPORÂNEO

RESUMO

Cada vez mais e com maior freqüência, questões relacionadas à ordem biolegal estão sendo ouvidas nos tribunais de justiça; um fato que requer um alto grau de conhecimento científico, ético e jurídico. Por esta razão, o presente trabalho está enquadrado no desenvolvimento discursivo e elementos de métodos jurídicos comparativos para lidar com as semelhanças e controvérsias que surgem no campo da bioética e da bioética, a fim de delimitar o campo de ação e o escopo. A análise da biolaw é assumida a partir do modelo jurídico e seu nexo com os direitos humanos. A racionalidade das contribuições técnico-científicas atuais, cujas contribuições são transcendentais, também é discutida. Dentro da aplicabilidade, o discurso é estendido sobre uma questão crítica como o direito a uma morte digna ou o poder de estender a vida, onde diferentes posições a favor e contra são expostas, reconhecendo a importância do reconhecimento dos direitos biológicos.

Palavras-chave: Biolaw; Direitos Humanos; Bioética, Distanásia

1 INTRODUCTION

The dynamics of development and social evolution with respect to biosciences, as well as scientific progress, have an enormous potential to affect the substantial living environment and the human being, which have been generating serious questions, many ethical and legal doubts and a chronic urgency to manage dynamic and rigorous answers from legal knowledge and ethical reflection. Therefore, biolaw, as an emerging discipline that has been generating a growing interest at the international global level, is an increasingly unquestionable reality (SALCEDO, 2020).

On the other hand, the current context is no stranger to the emerging threats to human rights in the face of the development of biomedical technologies, as well as to the identification of potential social risks that urge a judicial resolution in this field (VALDÉS, 2019).

Biolaw is not bioethics. Biolaw has been acquiring a special value in any legal system, becoming an accurate mechanism capable of guaranteeing an effective process of protection of those fundamental rights that, in a certain context, is related to each member of society, as well as to indicate the obligation of the State to protect those rights and promote their realization (VALDÉS, 2019; RENDTORFF & KEMP, 2019).





The current state of progress and new achievements in biomedicine now require exposure on the public agenda, social evaluation and normative and legal regulation (ROMANOVSKIY & ROMANOVSKAYA, 2021). At present, the problems derived from the great technological advances in the sciences, especially in the life sciences, are much more complex and require the points of view of experimental science, ethics and law together, since in the face of the increased intervening power of science in human activity, it would be appropriate to assume that what science and technology have made possible should be ethically accepted and, if so, what would be the legal limitations that regulate this aspect (SALCEDO, 2020). According to HORODOVENKO ET AL. (2020) many scientists share a similar opinion that the primary motive of bioethics is direct human intervention on natural processes with respect to both the environment and the nature of the human species.

The methodology used in the present research was based on general scientific and particular scientific methods of cognition (analytical-synthetic, deduction and induction methods and principles of comparative legal methods) and the technique of bibliographic research.

1.1 From Biolaw to Biolegal Frameworks

The principles of biolaw were published by the Danish philosophers RENDTORFF AND KEMP (2000) in the work "Basic ethical principles in European bioethics and biolaw", in which the authors justify four principles: autonomy, dignity, integrity and vulnerability (VALDÉS, 2019; ARAYA, 2023; MACHADO & TONEL, 2019; RAGNI, 2019); which emphasize the human condition as an end in itself capable of selfdetermination; the choice of the same being a necessity and effort to justify the protection of human beings with respect to the enormous development of biomedicine and biotechnology. According to VALDES (2019) to a certain extent the proposal of Rendtorff and Kemp was adequate since it grants a principalist body to biolaw and with it the normative and legally binding power; but it denotes carelessness about the epistemological and methodological differences between both fields, which generates an overlapping of normative dimensions. In this regard, VALDES (2021) mentioned that biolaw is fully capable of providing constitutional legal systems with a new and much more complete set of so-called fundamental rights, a fact that would allow States to comply with their international obligations by granting a more efficient status to these rights within the domestic jurisdictional frameworks.





Increasingly and with greater frequency, issues related to the biolegal order are being heard before the courts of justice; a fact that requires a high degree of scientific, ethical and legal knowledge. Therefore, the mastery of biolaw is for jurists a complementary element in their training, which has a high value on the basis of the social and legal reality of the moment (SALCEDO, 2020). Biolaw is justified and legitimized as a mature and independent discipline, due to the necessity of its praxis, it offers the capacity to identify new categories of damages and with it the establishment of the procedural bases for the constitutionalization of the so-called fourth generation human rights or biolaw. In short, by such means, the contribution of biolaw to reparatory law (especially in the field of the extracontractual liability of the State), constitutional law and criminal law becomes evident (VALDÉS, 2019).

The analysis of the international legal framework, in its essence, is more than an autonomous corpus of decrees and norms; therefore, biolaw should be established as the effective legal response of human rights to the various problems resulting from the continuous scientific and technological innovations (RAGNI, 2019). Biolaw is a legally binding legal model of a set of juridified principles and norms of constitutional rank with which to regulate biomedical practices, as well as to sanction their abuse and misuse (Valdés, 2019). States are the first to assume international responsibility for actions and wrongful acts that are linked to the violation of human rights in biolaw (TEN, 2019).

According to VALDÉS (2019) in the last two decades, three conceptions of biolaw have emerged globally. The first derives from the European school, which circumscribes biolaw as juridified ethics with binding norms to other general rules where the argumentation of the legal plane presupposes the moral argumentation and at this point biolaw would be the nexus between both argumentations delimiting between individual and collective law. The second, called Mediterranean, sees biolaw as the conglomerate of norms and principles with the power to regulate the legal aspect of bioethics, as a tributary discipline, and therefore it would only be an instrument of evolution for bioethics. The third, called the American conception, conceives biolaw as part of classical law applied to new legal problems in the biomedical field.

On the other hand, according to VALDÉS (2021), there is a close link between biolegal issues, constitutional law and human rights, which may lead to questions such as: What is more important: the integrity of the human being or the progress of society as a whole? How legally adequate is it to be able to use biomedical techniques for dysgenic purposes? In this regard, there is an urgent need to identify and delimit new binding legal frameworks to understand and regulate the legal scope derived from





biosciences. This urgency becomes even more evident if one takes into consideration certain objective events that elucidate the incompetence of traditional law when trying to address certain unprecedented legal problems generated by biomedical environments.

1.2 Human Rights from the field of biolaw

Endorsed in the first article and paragraph one of the Human Rights Act No. 39, these rights are inherent to every human person and must be protected as they are always the central matter of a modern state constitution (WIDJIASTUTI ET AL., 2020). Human rights, moral rights of the first order, are those inalienable rights that we all possess by virtue of being human, based on our inherent dignity and equal value as human beings (AGRAWAL, 2021).

According to AGRAWAL (2021) the concept of human rights is mainly of Western origin, mostly secular, and is best displayed in so-called liberal democracies. Considering that law is in a position to take responsibility for human welfare, let us see how the combination of international law and human rights can operate in the contemporary world where forests are burning, pandemic is on the rise and many conflicts remain unresolved (TRAVIESO ET AL., 2021).

The approach of a human rights model that generates a regulatory framework on the legislation of biomedical innovations in diagnosis and treatment requires, according to ROMANOVSKIY & ROMANOVSKAYA (2021), to specifically elucidate the risks that would affect fundamental human and civil rights and freedoms.

Under the spectrum of biolaw, the expansion of the scope of human rights implied abandoning the classic reductionist understanding of the human being as a non-political entity, because the enormous biomedical developments definitively placed the human body in the transcript of human rights (VALDÉS, 2019). Therefore, under this conception, the key notion for the new emerging right should be more than the person, it should assume the human being as a principle to achieve a universal scope.

In the wake of the global uncertainty resulting from the Covid-19 pandemic, TEN (2019) stated that there is an urgent need to sustain a strong commitment between international law and human rights with responsibility in bioethics, in order to preserve and consolidate what has been achieved so far in the construction of a globalized order based on shared rules and values that goes hand in hand with a policy structured on common values and international principles (TRAVIESO ET AL., 2021).





1.3 On biolaw, informed consent and end-of-life choice.

The right to life is a fundamental individual right and of collective interest (enshrined in Article 3 of the Universal Declaration of Human Rights) that invokes the safeguarding, with respect to the right, of physical integrity and that which refers to public health, which by its scope implies a dual obligation for the State: negative as well as positive. Therefore, the State shall seek to avoid any conduct that leads to alter or damage the life of its members and; at the same time, it has the duty to intervene for the removal of any situation that could potentially affect life or put it at risk (RENDTORFF, 2021; COLUSSI, 2019, MACHADO & TONEL, 2019).

According to RAGNI (2019), the issue of informed consent and the end of life, according to international law, there are no binding norms that deal with such a delicate issue in its full dimension, except for the adoption of the limited scope of the Oviedo Convention of 1997. In this aspect, the contribution of biolaw is fundamental because, as a derivation of law, it constitutes in itself an appropriate mechanism to understand and resolve the conflicts raised about the right of every human being to die with dignity (ARAYA, 2023). How the so-called informed consent and the end of life should be regulated has a current and too controversial validity due to the various moral and ethical implications that surround it (RAGNI, 2019).

The inevitable biological fact of death is beyond the domain or control of the individual and, despite being able to extend life by some biomedical means, the end is inexorable; but what is possible is to exercise control over the actions of how to confront the fact of dying with dignity and how to cope with the end of existence. At present, the debate on "dying with dignity" has too many angles and a series of arguments have been put forward for and against such an approach. This aspect, although controversial, may sound like a dystopia. In this regard, with all the current biotechnological advances, there is the fact of dystanasia or therapeutic overkill, a mechanism by which an attempt is made to prolong the life span of a terminal patient in conditions considered inhumane until the end is inevitable. This issue, considered as controversial, can be considered as a catalyst to promote a serious reflection on how to solve the problems related to the law on end-of-life care of the individual, for which possible solutions could be developed in the field of biolaw (ARAYA, 2023).

The phenomenon of suicide is related to the aforementioned. In this regard MACHADO & TONEL (2019) mentioned that suicide, or the intentional act of taking







one's own life, has become evident today within the debate agenda regarding the discussion on the importance of public policies aimed at preventing it and consequently protecting the fundamental human right to health and essentially the right to life.

Debates that seek to generate spaces for analysis and reflection on issues linked to the juncture between life and death - including suicide - such as the autonomy and freedom of human beings to dispose or not of their physical body, i.e., discussions on the right to life and death and the freedom of the individual and/or the voluntary choice towards death, versus the intervention of the State on the life of the individual through the state duty to protect life (MACHADO & TONEL, 2019).

On the other hand, authors such as GOUVEA & DEVAL (2018) have a different position by proposing the defense of the right to die as long as the conditions that make possible the achievement of existence are unbearable and unviable, which would be a condition unworthy of living and by default would be affecting the dignity of the person; then euthanasia, as well as suicide, is feasible to be admitted.

The notion of care, an important element of human life, refers to concern and interest and is the key to authenticity, since this concept expresses the nature of human beings and their choices based on morality. It tends to highlight two characteristics: (a) duality of the concept: the concept of care can adopt a negative nuance (burden, anxietyprovoking problems) and, on the other hand, it adopts a positive connotation attentionoriented practices, sympathy, solicitude); (b) the centrality of the concept of care to the human being which, understood at the ontological level, is related to tension and carelessness between the possible and that which is impossible, transforming into guilt and blaming the other for what could not be achieved (TEREC, 2021; FANNI, 2021). Regarding the care of patients at the end of life, AIZENBERG (2019) describes it from different positions. First, as a challenge for health personnel who must resign themselves to the impossibility of being able to heal, a situation that, being contrary to their training, will tend to generate frustration in most health professionals who will perceive such situations as professional failure and not so much as an unavoidable end to life. Secondly, from the perception of the patient and his or her family environment, since the fact of death is a certainty, but when it will happen is not.

Therefore, the recognition of palliative care as a human right includes two fundamental aspects: enforceability, to determine the punishability of actions that may ignore or restrict it, and universality, i.e. its radical importance regardless of individual conditions. Therefore, the human rights approach to palliative care allows promoting and advocating in a sustainable way from the patient's point of view, the guarantee that the





State fulfills its obligation towards patients in terms of guaranteeing their right to such care (AIZENBERG, 2019). Recognizing care means endowing it with two essential characteristics: its enforceability, i.e., the punishability of those acts that ignore and/or skip it; and its universality, its importance with respect to all people, regardless of their individual conditions.

1.4 Towards a constitutionalization of biolaw

The transcendence of the growing contemporary changes has been appreciated by the European Union and the EACEA (Education, Audiovisual and Culture Executive Agency), who have been promoting the project Biolaw as global tool for Human Rights protection (Pro Human Biolaw), whose main objectives are: (i) to provide legal-ethical answers to the challenges posed by the continuous advances and discoveries of modern science; (ii) to provide institutions with the competencies required to deepen and consolidate the teaching and consolidation of teaching and research in the field of human rights: (i) to provide ethical-legal responses to the challenges posed by the continuous advances and discoveries of modern science; (ii) to provide institutions with the skills required to deepen and consolidate teaching and research in the field of biolaw and human rights; (iii) to provide specialists in various fields with adequate tools that will enable them to amalgamate modern scientific knowledge with the demands of dignity derived from the recognitions embodied in human rights. The project is being coordinated by the University of Murcia in Spain and, in addition to European entities, four Latin American entities from Mexico and Costa Rica are participating, which have been developing interdisciplinary collaborative work based on ethics, scientific rigor and legal reflection, with a focus on law in general and health law and new technologies in particular, as well as applied philosophy and ethics, biomedicine, biotechnology, environment and health and human rights.

The possibility of a constitutionalization of biolaw is possible as long as the Constitution is assumed as a normative text and not only of a programmatic nature. According to VALDÉS (2019), this possibility is crucial in the process of assessing the importance of the recognition of bioderights, since this document constitutes the stage that exhibits the fundamental rights in the corresponding ubiquity under the new context of biomedical practices.

Contemporary development has been possible thanks to scientific-technological progress and it would be illogical to deny the intrinsic value it has generated beyond







possible defects; therefore, COLUSSI (2019) clearly stated that the freedom that scientific research may enjoy, which is central in this context, must be widely protected; but such enjoyment cannot take precedence over other rights and freedoms at stake, which cannot be 'suppressed' or 'sacrificed'. Therefore, the most rational options for dealing with the dilemma inherent in the 'dual role' posed by the development of some sciences and technologies are along the following lines: (a) being able to adopt an approach that is proportionate and balanced against freedoms and rights (manifested as laws and regulations), (b) a high role of involvement and participation of the central 'actors' (scientists, developers, companies) in the scenario through various channels that facilitate a plural and continuous dialogue, (c) generating mechanisms of control and verification of data and individuals, as well as the corresponding licenses for the use of equipment, materials and laboratories and, (d) development of a 'scientific conscience' that highlight the risks of a 'dual use' of research.

2. CONCLUSIONS

The importance of biolaw goes far beyond the enormous procedural or doctrinal contribution to the law, but also leads to a transcendental consequence by which it can, on the one hand, guarantee the mechanism of constitutionalization of new and necessary individual subjective rights or biolaw and, much more importantly, materialize a fair administration of justice and reparation of damages caused by the State.

Biolaw is capable of providing the biomedical field with greater legal certainty and security, and is able to delimit the adequacy of existing legal frameworks to support the rapid advance of biomedical technologies, and to weigh the possible impacts on the normative body of society with respect to biomedical and biotechnological empowerment.

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