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BIOETHICS AND HUMAN RIGHTS: PRINCIPLES AND CHALLENGES REGARDING ADVANCE DIRECTIVES IN BRAZILIAN LAW

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Abstract

The relationship between bioethics and human rights seeks to outline the guiding and connecting threads between two fields that reflect human reality and prompt us to look at ourselves - and, consequently, at humanity itself. Issues involving the end of life, especially those related to advance directives (ADs), encompass principles and guidelines found in the Universal Declaration on Bioethics and Human Rights, as well as in international documents and legislation. In Brazilian law, the absence of specific regulation leads to an analysis of the current landscape of the issue and raises questions regarding the drafting of a legal framework on the subject. In this context, language plays an important role in defining the scope of advance directives. For this analysis, the methodology adopted in this article is qualitative, grounded in legal doctrine, case law, and international documents. The objective is to demonstrate the foundations of the relationship between bioethics and human rights as supports for decision-making processes concerning end-of-life issues within the scope of advance directives. The presence of the principle of human dignity, in its universal character, guides this reflection.

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Keywords

Bioethics – Human rights – End of life – Advance directives - Dignity

1. Introduction

> However, when I entered the cinema at four or five o'clock, upon leaving I was struck by the sense of the passage of time, the contrast between two different temporal dimensions, inside and outside the film. I had entered in broad daylight and found, outside, darkness; the illuminated streets extended the black and white of the screen. The darkness sometimes diminished, at other times accentuated, the discontinuity between the two worlds, because the passage of those two hours that I had not lived was missing—I had been immersed in a suspension of time, or in the duration of an imaginary life, or in a leap back across centuries[1] [2].

The passage of time and the various scenarios that compose life and imagination establish parameters for the perception of the historical analysis of that same time and its reflections on the formation of the human being. For Italo Calvino, there was a life not lived during those two hours he spent in the cinema, which somehow separated him from the outside world. In the history of humanity, we can find these "moments of suspension" (as I call them), but this suspension is not devoid of meaning. On the contrary, silence or intervals of time may carry all forms of meaning and valuation of the lived moment, since to speak of suspension is not to speak of the absence of life.

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[1] Free translations of the original texts were made in this article.

[2] I. Calvino, *Autobiografia di uno spettatore*. In F. Fellini, *Fare um film*. Einaudi Editore, 2010, p. IX.

This perception connects with the theme of human rights in their human force, as the very name of these rights already suggests. The inherent characteristic of being human beings in itself reveals the importance of their relationship with Bioethics, a field where the analysis of ethical precepts and valuations about life and living converges. In this context, the need to reflect on medical and scientific progress with regard to human life means that bioethics is not an autonomous field of knowledge, but rather the confluence of diverse disciplines and the principles that underpin this reflection[3].

The connection between these spheres brings us back to the idea of suspension: the beginning and end of life today have various forms of delineation, especially—and above all—due to technological advances that innovate, expand, or modify birth and death. Therefore, there is a need for constant attention to these new contours, since the attenuation or reinforcement of the lines that define this scenario may either elevate or tarnish our very existence.

The analysis of end-of-life issues in Brazilian law, especially regarding the formulation of advance directives, is a process under construction. The absence of specific legislation on the subject refers us to internal regulations and interpretative foundations in comparative law and international documents. The methodology used in this article adopts a qualitative approach, through doctrine and case law on the subject. The selection of the legislative and regulatory frameworks of the countries analyzed was guided by the following criteria: their pioneering initiatives, the maturity and consolidation of their legal provisions on the subject, and their respective paths toward the adoption of relevant directives, which may provide valuable insights for the implementation of similar legislation in countries where such regulation has not yet been established. The exclusion of other countries that have enacted legislation on the matter reflects the fact that compiling an exhaustive survey of legal frameworks was not among the objectives of this study. It is noteworthy that all the countries examined are democratic states whose legal systems are grounded in the principles of individual autonomy and human dignity. The objective is to demonstrate the foundations of the relationship between bioethics and human rights as supports for decision-making regarding end-of-life choices within the scope of advance directives. The presence of the principle of human dignity, in its universal character, guides this reflection.

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[3] F. Busnelli, *Bioetica e diritto privato*: frammenti di un dizionario. Torino: G. Giappichelli Editore, 2001, p. 2.

2. Origins and use of the term "bioethics"

The reference to the emergence of bioethics points to a broad and profound landscape that is not limited to specific dates or events. The first medical schools that emerged during the Middle Ages maintained the tradition of citing the Hippocratic Oath at the end of the course as a prerequisite for the practice of the profession[4]. Subsequently, particularly in the context of the 19th century, the work of the English physician Thomas Percival on medical ethics portrays the ethical aspects of the practice of medicine. During this period, the first deontological codes also appeared, which "synthesize, based on the values inspired by Hippocratic ethics, the obligations that physicians must observe"[5].

In 1971, the term "bioethics" was recorded in connection with the link between science and humanity, and for many years this was considered the starting point for the use of the word "bioethics". In this context, the book *Bioethics: Bridge to the Future*, by the American biochemist Van Rensselaer Potter[6], He sought to imprint a sense of development and an evolutionary character, combining biological knowledge ("bio") with knowledge of the human value system ("ethics"). From this initial moment, two other stages of Potter's thought would come to characterize bioethics: the first, at the end of the 1980s, when he emphasized its interdisciplinary and comprehensive nature, naming it "Global," and the second, in 1998, when he redefined bioethics as "Deep," understanding it as an "ethical science that combines humility, responsibility, and interdisciplinary, intercultural competence, which enhances the sense of humanity"[7].

For many years, this reference framed the origin of the term "bioethics". However, studies show that the term "bio-ethics" was first used in 1926 by Fritz Jahr, a Protestant pastor, German philosopher, and educator, in the text *"Life Science and Ethics: Old Knowledge in New Clothes"*. Until recently, the first recorded use of the term was dated to 1927, also in a text by Jahr published in the journal *Kosmos*, in which the

[4] Historical elements and aspects related to the study of human autonomy are explored in greater depth in: C. Avancini Alves, *Bioética e direitos humanos*: análise sobre o início e o fim de vida. Porto Alegre: Editora Dialogar, 2021.

[5] Considerations and citation of this paragraph are included in: J. G. Fernández, *10 palavras-chave em bioética*. São Paulo: Paulinas, 2000, p. 13.

[6] V. R. Potter, *Bioethics: bridge to the future*. Englewood Cliffs, New Jersey: Prentice-Hall, 1971.

[7] Considerations on the stages of Potter's thought in: J. R. Goldim, *Bioética e complexidade*. In J. Martins-Costa; L. L. Moller (orgs). *Bioética e Responsabilidade*. Rio de Janeiro: Forense, 2009, p. 56.

author proposed the "assumption of ethical obligations not only toward human beings, but toward all living beings"[8].

For Jahr, plants and animals "are moral partners of human beings, and this relationship imposes obligations on humans to treat animals and plants appropriately"[9]. For this reason, according to José Roberto Goldim, Fritz Jahr's conception of bioethics was, like Potter's, comprehensive and broad, not limited to the fields of health and medicine. Jahr shared, along with Potter and André Hellegers[10], the need for special attention to the teaching of ethics in both professional and personal contexts, insofar as progress in the fields of science and technology required new positions in the social sphere[11].

Bioethics, according to Jahr, "is not a discovery of the present"[12], and he traces this understanding back to Saint Francis of Assisi[13], considered a great protector of animals. Jahr lived in a period of social transformations, and between 1926 and 1927, when he wrote and recorded the term "bioethics," there was a progressive advance in the life sciences, especially studies related to psychology[14]. Europe had not yet

[8] The text "Life science and ethics: old knowledge in new clothing" has the following reference: *Fritz Jahr: Wissenschaft vom Leben und Sittenlehre.* In: *Die Mittelschule. Zeitschrift für das gesamte mittlere Schulwesen, 1926, 40:604-6-5 [15.Dezember 1926]*. The quotation is made by: E-M. Engels, O desafio das biotécnicas para a ética e a antropologia. *Veritas – Revista Trimestral de Filosofia da PUCRS*. Porto Alegre, v. 50, n. 2, junho 2004, p. 218.

[9] J. R. Goldim, Revisiting the Beginning of Bioethics: the contribution of Fritz Jahr (1927). *Perspectives in Biology and Medicine*, volume 52, number 3 (summer 2009):377–80, by The Johns Hopkins University Press.

[10] André Hellegers used the term "bioethics" in 1970 to refer to emerging studies related to assisted reproduction. He was one of the founders of the Kennedy Institute of Ethics at Georgetown University, Washington, D.C., USA. More information in: J. R. Goldim, Bioética: origens e complexidade. *Rev HCPA* 2006;26(2):86-92; L. R. Walters, The birth and youth of the Kennedy Institute of Ethics. In: J. K. Walter; E. P. Klein (Editors). *The story of bioethics*: from seminal works to contemporary explorations. Washington, D.C.: Georgetown University Press, 2003, p. 215 ss.

[11] H-M. Sass, Fritz Jahr's Concept of Bioethics. *Kennedy Institute of Ethics Journal*, Vol. 17, No. 4, December 2007, p. 293.

[12] F. Jahr, "Life science and ethics: old knowledge in new clothing", *Fritz Jahr: Wissenschaft vom Leben und Sittenlehre, in: Die Mittelschule. Zeitschrift für das gesamte mittlere Schulwesen, 1926, 40:604-6-5 [15.Dezember 1926]*.

[13] J. Le Goff, *São Francisco de Assis*. Rio de Janeiro: Record, 2001.

[14] H-M. Sass, Fritz Jahr's 1927 Concept of Bioethics. *Kennedy Institute of Ethics Journal*, Vol. 17, No. 4, 2008, p. 208.

experienced the two World Wars, which would profoundly shape humanity itself[15]. In this sense, it is interesting to note that Jahr, even in that context, "outlined a broad approach to bioethics, which included human beings in a progressively complex relationship with society, with humanity, and with the biosphere" [16]. His attention to the development of disciplines concerned with the sustainability of the planet within the educational sphere forms the basis of the current panorama of bioethics education.

3. The concept of health and decision-making in the international scenario

It is important to emphasize that the context of Potter's first work reflects a period marked by the challenge of re-establishing the connection between medical practice and the patient, especially in the aftermath of the Second World War. A useful reference point to illustrate this circumstance is the concept of health defined after the fall of the Nazi regime, published in July 1946 in the Constitution of the World Health Organization (WHO). In this document, health is defined as encompassing mental and social well-being, and not merely physical well-being[17]. This definition, when analyzed within its historical context, signals the emergence of the idea of the welfare state, as well as "social medicine", which shifts healthcare from a private sphere to a public responsibility.

In this context, the principles of freedom and autonomy acquire strong significance, particularly due to the development of documents aimed at protecting the patient through adequate processes of information. Informed consent is one of the key elements in the bioethical debate, as it directly involves patient decision-making, something that had been disregarded during the totalitarian period. Thus, it is noteworthy that the question of limits to the right to treatment begins to emerge around 1970, due to two phenomena: the economic crisis of 1973 and technological progress, which made it possible to sustain the lives of individuals who, without such techniques, would not have survived. Questions such as "is there an obligation, in the

[15] The analysis of Fritz Jahr's life in this period in: L. Pessini, At the origins of bioethics: from Potter's bioethical creed to Fritz Jahr's bioethical imperative. *Rev bioét (Impr.)* 2013; 21 (1): 9-18.

[16] J. R. Goldim, "Revisiting the beginning of bioethics: the contribution of Fritz Jahr (1927)". *Perspectives in Biology and Medicine* 52.3 (Summer 2009): 377(4). Academic OneFile. Gale. CAPES. 18 Aug. 2009.

[17] The concept of "health" as stated in the Constitution of the World Health Organization: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity". Available at::http://www.who.int/governance/eb/who_constitution_en.pdf, accessed on April 29, 2026.

name of justice, to provide all types of medical treatment in a given clinical scenario?" began to arise during this period[18].

There was also a transformation in the physician–patient and medicine–society relationship after 1960. Previously, the physician made decisions regarding treatment, a situation that changed in the mid-1970s. According to David Rothman, the impact of these events "was to make the invisible visible. People from outside the medical field—namely lawyers, judges, and academics—entered every nook and cranny of the process of giving medicine an exceptional prominence on the public agenda and of turning the topic into public discourse"[19]. In this sense, medical practice became part of an economic context, as it came to be perceived as an element that generates "possibilities of life," meaning that as individuals have greater chances of "living"[20] society as a whole benefits. The connection between well-being, technological development, and social elements directly influences the biomedical scenario. Currently, "technology operates in concrete situations that depend, contextually, on a moral quality. Technology creates a moral issue, and this circumstance produces the field in which a given decision will take place"[21].

The earliest known citation related to a situation involving consent and information dates back to 1767[22]. In the English case *Slater v. Baker and Stapleton*, the plaintiff, Slater, hired physicians Baker and Stapleton to treat a fracture in his leg. Without the patient's consent, the physicians deliberately disrupted the bone callus in order to

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[18] "This fact, it might be observed, was nothing else but a particular example of something that medicine had transformed into a norm – anti-Darwinian action. If nature, as Darwin asserted, selects the fittest and condemns the weakest and the least fit to death, then medicine acts in exactly the opposite way. This meant that the number of the chronically and terminally ill (mentally retarded children, the gravely infirm, the elderly etc.) became ever greater, something which brought with it the so-called 'cost-explosion'. Once again the question was posed as to whether justice requires that all these sick people are taken care of using all means available. What limits should be placed on their treatment? From what point of departure does the obligation to treat and care for them cease to be total (or one of justice) and become one which is incomplete or a matter of charity?". D. Gracia, The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 48.

[19] D. J. Rothman, *Strangers at the bedside*: a history of how law and bioethics transformed medical decision making. New York: Aldine de Gruyter, 2003, p. 03.

[20] D. Gracia, The economy and medicine in the twentieth century. *Dolentium Hominum*, No. 43, Year XV, No. 1, 2000, p. 49.

[21] R. Buchholz; S. B. Rosenthal, Technology and business: rethinking the moral dilemma. *Journal of Business Ethics*, volume 41, Nos. 1/2, November (II), December (I) 2002, p. 48.

[22] J. Clotet; C. F. Francisconi; J. R. Goldim (Org.). *Consentimento informado e sua prática na assistência e pesquisa no Brasil*. Porto Alegre: EDIPUCRS, 2000, p. 29.

apply a non-conventional method during the healing process. Slater accused the physicians of ignorance and malpractice for causing a new fracture, and physicians who testified as experts in the case stated that the procedure adopted by Baker and Stapleton was not customary and that, in their place, they would have sought the patient's consent. The court ruled against the physicians for breach of contract in the doctor–patient relationship. The Slater case represents an important example of how judicial decisions may be influenced by both practical and theoretical considerations, "resulting in a kind of lack of clarity that has hindered the understanding of the law regarding informed consent since its earliest development"[23].

In the field of research, the first use of a document that can be considered similar to informed consent occurred in October 1833. Physician William Beaumont established a contract with patient Alexis St. Martin, who received housing, food, and the sum of 150 dollars for one year in exchange for making himself available to the physician for any experiments that could be performed on his body. As a result of a gunshot wound, the patient's stomach remained open, which allowed the physician to directly observe the interior of St. Martin's stomach for many years. In this way, Beaumont was able to conduct a large number of experiments related to the digestive process[24].

The term "informed consent" was coined in 1957 in a judicial ruling resulting from the case *Salgo v. Leland Stanford Jr. University Board of Trustees*, decided in California (USA)[25]. Martin Salgo suffered permanent paralysis following a diagnostic aortography and brought an action against the university, accusing the physicians of negligence and of failing to inform him about the possible adverse outcomes resulting from the procedure. The Court emphasized that the physician had a duty to disclose all necessary facts that could support the patient's decision regarding the proposed treatment.

The decision in the *Salgo* case introduced new elements into the legal sphere. According to Ruth Faden and Tom Beauchamp[26], unlike previous rulings, the aforementioned judgment was not concerned solely with verifying whether consent

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[23] R. R. Faden; T. Beauchamp, *A history and theory of informed consent*. New York, Oxford: Oxford University Press, 1986, p. 116.

[24] J. R. Goldim, *O consentimento informado numa perspectiva além da autonomia*. *In* R. Timm de Souza, (Org) et all. *Ciência e Ética*: os grandes desafios. EDIPUCRS, 2006, p. 46.

[25] J. R. Goldim, *O consentimento informado numa perspectiva além da autonomia*. *In* R. Timm de Souza, (Org) et all. *Ciência e Ética*: os grandes desafios. EDIPUCRS, 2006, p. 46.

[26] R. R. Faden; T. Beauchamp, *A history and theory of informed consent*. New York, Oxford: Oxford University Press, 1986, pp. 125 e 126.

had been given in relation to the proposed procedures, but also whether it had, in fact, been informed. The Court established what became known as "informed consent" by invoking the importance of autonomy, in the sense that clarification of all elements of consent—its nature, consequences, harms, benefits, risks, and alternatives of a given treatment—should be considered essential so that the patient would truly understand what they were choosing.

Moving ahead and establishing an initial connection between bioethics and human rights, it is stated that the report of UNESCO's International Bioethics Committee on Consent affirms that informed consent is a fundamental principle, highlighting the importance of autonomy in the study of medical ethics. The document explains that the need for informed consent in biomedical research gained prominence after the Nuremberg trials, which revealed human experimentation procedures on prisoners in concentration camps, and remained necessary in light of experiments conducted after the Second World War itself. According to Rothman, throughout much of the 19th century, such experiments were carried out in the United States and were considered a kind of "cottage industry that evolved into a national program"[27]. There was a kind of justification for conducting research without the consent process, based on the military effort of soldiers and the country. In 1941, the Committee on Medical Research (CMR) was created, and its members helped develop and distribute medicines whose experiments were carried out in orphanages, asylums, and prisons, without consent.

> Since these investigations were integral to the military effort, the rules of the battlefield seemed to apply to the laboratory. Researchers were no more obliged to obtain the permission of their subjects than the Selective Service was to obtain the permission of civilians to become soldiers. One part of the war machine conscripted a soldier, another part conscripted an experimental subject, and the same principles held for both[28].

The period between the end of the Second World War and Henry Beecher's report (1966)[29] was considered the "golden years" of research, a period in which the

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[27] D. J. Rothman, *Strangers at the bedside*: a history of how law and bioethics transformed medical decision making. New York: Aldine de Gruyter, 2003, pp. 30-31.

[28] D. J. Rothman, *Strangers at the bedside*: a history of how law and bioethics transformed medical decision making. New York: Aldine de Gruyter, 2003, p. 49.

[29] Henry Beecher, Professor of "Research in Anesthesia" at Harvard Medical School, published the article "Ethics and Clinical Research" in the *New England Journal of Medicine* (NEJM), which caused great commotion in the scientific community because it gathered 50 articles published in 11 well-known scientific journals and, after the establishment of the Nuremberg Code, revealed significant

principles of voluntary participation and consent were not followed. The media and American society did not give importance to the Nuremberg Code, because they established a dichotomy between physicians and the so-called "Nazis": the guilty parties were not the doctors or scientists, but Hitler's followers. Another relevant factor in this context was the argument, advanced by several studies, that the atrocities committed and judged at Nuremberg were the result of governmental interference in the conduct of research. "Science was pure – it was politics that was corrupting. Hence, state control over medicine through regulations that intruded in the private relationship between doctor and patient or investigator and subject were likely to pervert medicine"[30].

A few years after Henry Beecher's report, a public denunciation emerged regarding an experiment conducted in Tuskegee, in the state of Alabama (USA), in which antibiotic treatment was withheld from Black individuals with syphilis as part of a study on the progression of the disease[31]. There was a strong reaction from public opinion against this fact, which led to the establishment of the so-called "National Commission" (*National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research*, 1974–1978). This commission set forth the parameters to be observed in research involving human subjects, especially with regard to members of vulnerable groups. The *Belmont Report*, which compiles the Commission's deliberations on this matter, became an important document for the analysis and development of bioethics.

Another case that generated wide debate in the United States occurred in 1975, involving the young American Karen A. Quinlan. It is reported that, after she entered a coma, her adoptive parents—"practicing Catholics, advised by their parish priest"—faced with the prognosis of the irreversibility of their daughter's return to a conscious life, requested that the hospital administration disconnect the respirator that was keeping her alive"[32]. Legal proceedings were initiated, and the Supreme Court of the

methodological and ethical deviations. He showed that in only two of the cited studies had informed consent from research participants been obtained. J. Clotet; C. F. Francisconi; J. R. Goldim (Org.). *Consentimento informado e sua prática na assistência e pesquisa no Brasil*. Porto Alegre: EDIPUCRS, 2000, p. 45.

[30] D. J. Rothman, *Strangers at the bedside*: a history of how law and bioethics transformed medical decision making. New York: Aldine de Gruyter, 2003, p. 63.

[31] Information from this paragraph in: J. G. Fernández, *10 palavras-chave em bioética*. São Paulo: Paulinas, 2000, p. 17.

[32] Citations from this paragraph i J. G. Fernández, *10 palavras-chave em bioética*. São Paulo: Paulinas, 2000, p. 18.

State of New Jersey recognized the young woman's "right to die in peace and with dignity". This case sparked significant controversy and paved the way for the development and recognition, in the United States, of advance directives.

The trajectory outlined thus far demonstrates the context in which the term bioethics came to occupy social, political, and legal discussions during the period in which the first institutions were established and important works on the subject were published. Over the years, bioethics has become a field of study present in numerous countries[33]. Beyond the academic sphere, the connection between clinical care and research plays a decisive role in the reflection on and application of bioethical principles involving the physician–patient relationship. In Brazil, a study conducted by José Roberto Goldim offers the concept of so-called "Complex Bioethics", which seeks to provide an integrated perspective on the decision-making process involved in practical bioethical issues. According to the author, "the proper identification of the bioethical problem or conflict is the first step toward its possible resolution"[34].

This problem, following the framework of Complex Bioethics, arises from the discomfort it generates for the professional, the patient, the family member, or a third party involved in the situation. The problem is contextualized in the present, while facts, circumstances, theoretical frameworks, and case repertoires are drawn from the past to form a "historical present" during the reflective process itself. The possible alternatives for resolving the problem and their respective consequences are foreseeable projections; facts allow for a clearer identification of the problem, while circumstances may reveal characteristics that are sometimes hidden and not immediately apparent. According to Goldim, "the identification of ethical, moral, legal, social, biological, clinical, professional, among other aspects, is what enables a comprehensive view of the problem to be addressed". Thus, bioethics can be understood as a space of interface among the different aspects involved in a given problem"[35].

Interdisciplinarity becomes a fundamental element in bioethical reflection, especially due to the relationships established among different fields of knowledge, which enrich the debate and the applicability of the information obtained or received in any decision-making process involving the biomedical sphere. Thus, the interface

[33] H.A.M.J. ten Have, Bioethics education. In H.A.M.J. ten Have, B. Gordijn (eds.), *Handbook of Global Bioethics*, DOI 10.1007/978-94-007-2512-6_96, # Springer Science+Business Media Dordrecht 2014.

[34] J. R. Goldim, *Bioética e complexidade*. In J. Martins-Costa; L. L. Moller (orgs). *Bioética e Responsabilidade*. Rio de Janeiro: Forense, 2009, p. 69.

[35] J. R. Goldim, *Bioética e complexidade*. In J. Martins-Costa; L. L. Moller (orgs). *Bioética e Responsabilidade*. Rio de Janeiro: Forense, 2009, p. 69.

between bioethics and human rights constitutes a rich and fruitful field for inquiry and for the formulation of guidelines concerning life and the protection of the human person in all its dimensions.

4. The relationship between bioethics and human rights

The preceding sections have already indicated several elements of connection and interface between bioethics and human rights. It is evident that, in parallel with the affirmation of human rights in the post-war period, technological advances and their repercussions in the field of health were being discussed. If the milestone linking rights concerning the human being as rights of all humanity occurred at the end of the Second World War, it becomes clear that, among the aspects that actively participate in this totality, health stands out as a determining factor in the protection of the human being and in the development of their personality.

The reference to the World Health Organization (WHO) definition of health as a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity, reveals the extent to which health acquires an inclusive character, independent of gender or race, constituting a state duty to ensure social development. In this scenario, the formation of the United Nations (UN) reflects the emergence of a new international order and establishes a new model of conduct in international relations.

Among the international human rights documents published after the Second World War, it is important to highlight those that establish principles relevant to biomedical issues. Article I of the Universal Declaration of Human Rights (1948) affirms the inherent dignity of every human being, who is entitled to equal and inalienable rights. Article III guarantees the right to life, and Article XII provides for the protection of privacy and personal information. This document, "reviving the ideals of the French Revolution, represented the historical manifestation that, at last, at the universal level, recognition had been formed of the supreme values of equality, liberty, and fraternity among human beings (…)"[36]. Its implementation requires the systematic effort of each country so that society incorporates human rights as an effective practice in community life. As a declaration, the document is technically non-binding. However, the recognition of these rights must be exercised within the framework of international law. It has been stated that "the Universal Declaration has been

[36] F. K. Comparato, *A afirmação histórica dos direitos humanos*. São Paulo: Saraiva, 2003, p. 223. "Article I – All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood".

conceived as the authoritative interpretation of the expression 'human rights' contained in the United Nations Charter, and for this reason it has binding legal force"[37].

It is noted that Constitutions drafted after the Second World War incorporated general principles, currently regarded as sources of law, which establish "basic rules applicable to a given legal institute or branch of law, in order to assist legal practitioners in the pursuit of justice and social harmony"[38]. The reference to legal principles also relates to Robert Alexy's conception, for whom principles are norms[39] that require something to be realized to the greatest extent possible, within the existing legal and factual possibilities. For this reason, principles are "optimization commands", characterized by the fact that they can be fulfilled in varying degrees, and the appropriate extent of their fulfillment depends not only on factual possibilities but also on legal ones. The scope of legal possibilities is determined by opposing principles and rules[40]. In this way, they are norms that prescribe ends to be achieved[41], performing an interpretative function and providing coherence to the legal system[42].

In the field of bioethics, the aforementioned Belmont Report, which brought together the conclusions of the National Commission created in the 1970s in the United States, identifies the principles that have become reference points in this area: the principle of beneficence (or non-maleficence), autonomy, and justice. With these, "bioethical problems are no longer analyzed according to deontological codes, but on the basis

[37] F. Piovesan, *Direitos Humanos e o Direito Constitucional Internacional*. São Paulo: Saraiva, 2012, p. 211.

[38] F. Tartuce, *Manual de Direito Civil*: volume único. Rio de Janeiro: Forense; São Paulo: Método, 2012, p. 22.

[39] According to Humberto Ávila, norms are not texts nor the set of texts themselves, "but rather the meanings constructed from the systematic interpretation of normative texts". H. Ávila, *Teoria dos princípios*: da definição à aplicação dos princípios jurídicos. São Paulo: Malheiros Editores Ltda., 2002, p. 22.

[40] It is established that the reference to principles does not aim to discuss their relationship with rules, but rather to outline their importance in the connection between human rights and bioethics. However, to briefly illustrate the issue, it may be noted that, according to Alexy, rules differ from principles insofar as they are norms that can either be complied with or not. If a rule is valid, what it requires must be done. Therefore, rules contain "determinations" within the realm of what is factually and legally possible. This means that the distinction between rules and principles is qualitative rather than one of degree. "All norms are either rules or principles". R. Alexy, *Teoría de los derechos fundamentales*. Madrid: Centro de Estudios Políticos y Constitucionales, 2002, p. 87.

[41] H. Ávila, *Teoria dos princípios*: da definição à aplicação dos princípios jurídicos. São Paulo: Malheiros Editores Ltda., 2002, p. 15.

[42] E. R. Grau, *Ensaio e discurso sobre a interpretação/aplicação do direito*. São Paulo: Malheiros Editores Ltda., 2002, p. 180.

of the aforementioned principles and the procedures derived from them"[43]. As for the principles of medical ethics, they are configured as general guidelines "that leave considerable room for judgment in specific cases and that provide substantive guidance for the development of more detailed rules and policies"[44].

Beauchamp and Childress define the principle of beneficence as a set of norms aimed at providing and weighing benefits against risks and costs, while non-maleficence prevents the infliction of harm. Respect for autonomy lies specifically in respecting the decision-making capacity of autonomous individuals, whereas the principle of justice consists of a set of norms for fairly distributing benefits, risks, and costs[45].

It is important to note, from the perspective of Francesco Busnelli, that the general principles of different and well-known legal systems, due to their diversity, lead to the prospect of different practical solutions both in doctrinal, jurisprudential, and legislative spheres. Thus, "In the various contexts in which bioethical issues arise, and where specific rules have not yet been formulated, recourse to principles proves fruitful in identifying coherent legal responses; moreover, in contact with practice, these same principles are enriched with new possibilities"[46].

The relationship between bioethics and human rights has this necessary connection with principles, especially through the observation that they interact, each within its own conceptual sphere, with internationally issued declarations and treaties, and that they carry an effective indication of applicability. In this sense, one may take as an example the relationship among principles such as equality, freedom, and dignity, which, in the words of Fábio Konder Comparato, reveal that human dignity "does not consist merely in the fact that, unlike things, a person is a being considered and treated, in itself, as an end in itself and never as a means to achieve a given result. It also derives from the fact that, through rational will, only the person lives under conditions of autonomy, that is, as a being capable of guiding themselves by laws they themselves establish"[47].

With this society-oriented perspective, after the Universal Declaration of Human Rights there followed the institutionalization of human rights. In 1966, the

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[43] J. G. Fernández, *10 palavras-chave em bioética.* São Paulo: Paulinas, 2000, p. 22.

[44] T. L. Beauchamp; J. F. Childress, *Princípios de ética biomédica.* São Paulo: Edições Loyola, 2002, p. 55.

[45] T. L. Beauchamp; J. F. Childress, *Princípios de ética biomédica.* São Paulo: Edições Loyola, 2002, p. 56.

[46] F. Busnelli. *Bioetica e diritto privato*: frammenti di un dizionario. Torino: G. Giappichelli Editore, 2001, p. 7.

[47] F. K. Comparato, *A afirmação histórica dos direitos humanos*. São Paulo: Saraiva, 2003, p. 21.

International Covenant on Civil and Political Rights included, in Article 7, the importance and necessity of informed consent as an instrument that attests to adequate information in the decision-making process in the biomedical field. This understanding is connected to Article 12 of the International Covenant on Economic, Social and Cultural Rights, published in the same year, by emphasizing access to health and the full exercise of this right as a foundational element in the affirmation of human rights.

The development of new technologies in the years following these documents led international organizations to new reflections. The Council of Europe, through the Convention on Human Rights and Biomedicine held in 1997, also known as the "Oviedo Convention", seeks to harmonize the framing of reflections and solutions for the questions or conflicts that arise in this field. According to Roberto Andorno,"Aware of the need for minimal common standards, some intergovernmental organizations began in the mid-1990's to promote an international consensus on some basic norms relating to biomedicine"[48]. The Universal Declaration on Bioethics and Human Rights results from this context.

In this scenario, following the Oviedo Convention, three other important documents addressing biomedical issues emerged on the international stage: the Universal Declaration on the Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003), and the Universal Declaration on Bioethics and Human Rights (2005). The latter is of great importance, as it is the first international document that, on a global scale, establishes the relationship between bioethics and human rights.

Among the general provisions of the Universal Declaration on Bioethics and Human Rights, one highlights its contribution to respect for human dignity and the protection of human rights, ensuring respect for human life and fundamental freedoms in a manner consistent with international law, as well as the promotion of equitable access to advances in medicine, science, and technology. The document then sets out its principles and their application, as well as how the promotion of the Declaration should be carried out by States, through the educational sphere, and through international cooperation, in addition to presenting UNESCO's monitoring initiatives. In its final provisions, it is emphasized that the Declaration "must be understood as a whole and its principles must be understood as complementary and

[48] R. Andorno, Global Bioethics and Human Rights. *Medicine and Law*, 2008, 27(1):1-14.

interdependent. Each principle must be considered in the context of the others, as appropriate and relevant, according to the circumstances"[49].

An example that can be mentioned in this context concerns Article 5, which provides that "the autonomy of persons in decision-making, provided that they assume their respective responsibility and respect the autonomy of others, must be respected. In the case of persons unable to exercise their autonomy, special measures must be taken to protect their rights and interests". According to an analysis developed by Donald Evans of this provision of the Declaration, bioethics emerges from a diverse range of contexts, with two of them standing out: the first refers to the emergence of notions of human and individual rights during the second half of the twentieth century, and the second reflects the reaction to abuses committed in the field of human rights during the same period in relation to clinical research practices[50].

According to the author, the 1948 Universal Declaration of Human Rights clearly referenced the protection of these rights by stating that all human beings are born free and equal in dignity and rights, a document that "followed hard on the heels of the Nuremberg Code (1947), which issued from the Nuremberg trials of medical researchers who were accused and convicted of committing crimes against humanity in the name of medical research". In this context, the Code presents informed consent as a tangible expression of respect for autonomy. In emphasizing the importance of connecting bioethics with human rights, "it became clear to those developing the Universal Declaration on Bioethics and Human Rights that an article enjoining respect for the autonomy of persons involved in medical treatment and research was an absolute requirement"[51].

This requirement is grounded in the inherent humanity of each person, which makes it possible to speak of the universality of human rights. The universal character present in the analysis of human rights, insofar as they are considered inherent to every human being, is reflected in the possibility of their application across a broad and significant spectrum of cultural diversity. It is in this sense that countries with different political, religious, or social orientations ratify or adhere to treaties and

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[49] Universal Declaration on Bioethics and Human Rights. UNESCO – United Nations Educational, Scientific and Cultural Organization. Available at: unesdoc.unesco.org/images/0014/.../146180por.pdf. Accessed on April 30, 2026.

[50] D. Evans, *Article 5: Autonomy and individual responsibility*. In *The UNESCO Universal Declaration on Bioethics and Human Rights*: background, principles and application. Edited by Henk A. M. J. ten Have and Michèle S. Jean. Paris: UNESCO 2009, p. 111.

[51] D. Evans, *Article 5: Autonomy and individual responsibility*. In *The UNESCO Universal Declaration on Bioethics and Human Rights*: background, principles and application. Edited by Henk A. M. J. ten Have and Michèle S. Jean. Paris: UNESCO 2009, pp. 111-113.

conventions on this subject, since "it is essentially a right of protection, marked by its own logic, and aimed at safeguarding the rights of human beings rather than those of States"[52].

The Brazilian legal system enshrines, in Article 4, II, of the Federal Constitution, the prevalence of human rights as a guiding principle in international relations. Following the enactment of Constitutional Amendment No. 45 of 2004, paragraph 3 was added to Article 5 of the Constitution, which states: "International treaties and conventions on human rights that are approved in each House of the National Congress, in two rounds of voting, by three-fifths of the votes of their respective members, shall be equivalent to constitutional amendments". This provision has given rise to interesting debates regarding the hierarchy of norms; however, for the purposes of the present work, it is important to emphasize directly that the theme of human rights carries constitutional force[53].

It should be emphasized that the Universal Declaration on Bioethics and Human Rights is not a treaty. However, as previously noted, the worldwide recognition of human rights and the importance of ensuring and preserving their protection of the human person lead to a binding interpretative force of its provisions, associated with the principles that underpin such interpretation. This constitutes what is referred to as the "sense of direction"[54] that seeks to be offered to society, especially when we refer to issues that confront us with our own humanity.

5. Overview of advance directives in different legal systems

The line established between bioethics and human rights has its trajectory grounded in respect for autonomy and in the inherent dignity present in every human being. The reference, in this context, to end-of-life issues is highly relevant due to the various international documents and legal frameworks concerning so-called "advance directives" (ADs), which introduce a new perspective on the patient's capacity for decision-making and the preservation of their will even when they are unable to express themselves in a clinical context.

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[52] A. A. Cançado Trindade, *Tratado de Direito Internacional dos Direitos Humanos*, volume I. Porto Alegre: Sergio Fabris Editor, 1997, p. 20.

[53] Debate present in: F. Piovesan, *Direitos Humanos e o Direito Constitucional Internacional*. São Paulo: Saraiva, 2012, pp. 127-129.

[54] C. Lafer, *A Internacionalização dos Direitos Humanos*: Constituição, Racismo e Relações Internacionais. Barueri, SP: Manole, 2005, p. 13.

In Brazil, this topic is undergoing a phase of assessment regarding the effectiveness of the document and the need (or not) for specific legislation on the matter. Advance directives are included in the ethical norms of the Federal Council of Medicine (CFM), through Resolution No. 1.995/2012. In its Article 1, they are defined as "the set of wishes, previously and expressly manifested by the patient, regarding care and treatments that they want, or do not want, to receive at the moment when they are unable to express, freely and autonomously, their will".

The publication of the Resolution generated broad debate regarding the implementation of the document, following the path of international cases that have become emblematic for the analysis of the topic. It is important to remember that social, cultural, and economic aspects play a decisive role in this discussion, since the perception of end-of-life issues brings together elements that confront us with our decision-making power. This assertion rests on what I call the "temporality factor", that is, the stance assumed at a given moment in our lives may change due to new perceptions we acquire throughout our existence, or due to new medications that may assist in curing a given disease—factors that must be taken into account when drafting advance directives.

In this context, it becomes clear that the rapid development of biomedical technology brings, at the same time, numerous benefits in terms of human longevity and also raises reflection on the non-mechanization of dying and the need not to forget the naturalness of the end of life. In order to situate the effects of Resolution No. 1.995/2012 and of legislation addressing the topic in the international context, it is important to outline some aspects regarding the origin of the document and to analyze the different designations it has received throughout its evolution.

The article "Due Process of Euthanasia: The Living Will, A Proposal", by Luis Kutner, became a reference point for the emergence of the discussion on advance directives. Written in the 1960s, it describes a concrete case that occurred in a hospital in the United States, when the young student Robert Waskin shot his mother three times, killing her in her hospital bed. He explained that "She asked me to do it"[55], because she was in an advanced oncological stage. Waskin was arrested and charged with first-degree murder by the Grand Jury of Cook County, Illinois, but was later acquitted when the jury initially ruled that he had acted under insanity and, subsequently, in a new decision, he was no longer considered insane. The case sparked an intense debate on euthanasia and its relationship with so-called "mercy killing". According to Kutner, the absence of standards of conduct to guide cases involving

[55] L. Kutner, (1969) "Due Process of Euthanasia: The Living Will, a Proposal", *Indiana Law Journal*: Vol. 44: Iss. 4, Article 2.

these two issues prevented an adequate legal procedure in any claim addressing such matters[56].

The author also discusses fundamental issues such as the right to life and privacy, as well as aspects related to one's own body, including the patient's right to refuse or consent to a given type of treatment. In this line of reasoning, Kutner refers to the "living will" as the document through which a patient could establish the types of medical procedures to which they would wish to be subjected. It is interesting to reproduce his words when he states that:

> The law clearly prohibits mercy killing, even if undertaken at the patient's request. Thus, the patient cannot request another to end his life. Such an action would subject the actor to prosecution for murder. But an individual does have the right to refuse to permit a doctor to treat him, even if such treatment would prolong his live. If a doctor should act contrary to his wishes, he would be subject to liability[57].

He therefore emphasizes that there is a fundamental difference between asking someone to end one's own life and choosing to refuse treatment, even if such treatment would prolong life.

After the event described by Kutner, another case occurred in the 1980s that would shape the issue of advance directives in the United States. A young American woman, Nancy Cruzan, suffered a car accident in the state of Missouri and was diagnosed with permanent brain damage[58]. She survived through assisted nutrition and hydration procedures for several years, until her parents and husband requested the withdrawal of this intervention. The physicians refused to comply with this request without judicial authorization. In 1990, the Missouri court granted the family's request. Among the arguments in the decision, it was noted that Nancy, when she was 20 years

[56] "(…) the present state of the law, as it is evolving from judicial practice, may in effect be permitting mercy killing without adequate protection for the victim whose death may be unwarranted and uncanted. Clearly, the lack of definiteness in the present state of the law does not comport with the notions of due process of law". L. Kutner, (1969) "Due Process of Euthanasia: The Living Will, a Proposal", *Indiana Law Journal*: Vol. 44: Iss. 4, Article 2, pp. 542-543.

[57] L. Kutner, (1969). Due Process of Euthanasia: The Living Will, A Proposal. *Indiana Law Journal*: Vol. 44: Iss. 4, Article 2, p. 550.

[58] The author notes that this topic was also addressed in two other texts of her authorship: C. Avancini Alves, Linguagem, Diretivas Antecipadas de Vontade e Testamento Vital: uma interface nacional e internacional. *Revista Bioethikos*. Centro Universitário São Camilo. 2013;7(3) e C. Avancini Alves, Diretivas antecipadas de vontade e testamento vital: considerações sobre linguagem e fim de vida. *Revista Jurídica*, ano 61, maio de 2012, nº 427, pp. 89-110.

old, had reportedly told a roommate that she did not want to be kept alive by artificial means if anything were to happen that left her with less than half of her normal capacity for autonomous life. After the accident, it was established that she was in a state of manifest incapacity[59].

In the wake of this case, the United States Congress passed the so-called *Patient Self-Determination Act (PSDA)*, which came into effect on December 1, 1991[60]. The PSDA provides three ways to implement advance directives, defined in that law as "Advance Directives": (a) an explicit expression of one's own will (living will); (b) durable power of attorney for health care (PRCS – durable power of attorney for health care), it being important to note that "attorney," in this context, does not specifically mean "lawyer," but rather a person granted authority to represent another; and (c) advance care medical directive (DACM – advance care medical directive), i.e., an advance decision or order regarding medical care.

It should be noted that the expression *living will* cannot be literally translated into Portuguese, since "will" may indicate both a desire for something that one wishes to happen in the future[61], as well as the document in which one declares the intended disposition of one's own assets[62]. This caution is important because language has a strong influence on the formation of our thinking. A study indicates that several pieces of research "have been showing how language shapes more fundamental dimensions of human experience: space, time, causality, and relationships with others"[63]. To this perception, one may add the fact that the drafting of a document related, in this case, to expressions of will regarding a given treatment may generate different interpretations regarding the scope of its application.

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[59] On Nancy Cruzan's gravestone is the following inscription: "Born on July 20, 1957. Departed on January 11, 1983. At peace on December 26, 1990". G. Tepedino; A. Schreiber, O extremo da vida: eutanásia, *accanimento terapeutico* e dignidade humana. *Revista Trimestral de Direito Civil*, Ano 10, vol. 39, julho a setembro de 2009, p. 15.

[60] J. Clotet, Reconhecimento e institucionalização da autonomia do paciente: um estudo da 'The Patient Self-Determination Act'. *Bioética*, 1993;1: 157-163.

[61] "You use will to indicate that you hope, think, or have evidence that something is going to happen or be the case in the future", "use will to indicate someone's intention to do something", "You use will in order to make promises and threats about what is going to happen or be the case in the future". Collins COBUILD Dictionary, 2006.

[62] "A will is a document in which you declare what you want to happen to your money and property when you die". Collins COBUILD Dictionary, 2006.

[63] Citations from this paragraph in: L. Boroditsky, Como a linguagem modela o pensamento. *Scientific American/Mente Cérebro*, Ano XIX, nº 247, Agosto 2013, pp. 30-35.

An example of this statement lies in the wording and translation of terms related to the topic not only in the legislative sphere (laws addressing this issue in some countries) but also in international documents. The Council of Europe, as an institution that defines the general political orientations and priorities of the European Union, simultaneously seeks the development of common standards within the European framework on bioethics-related issues. In 1997, it published the "Convention on Human Rights and Biomedicine," also known as the "Oviedo Convention"[64]. In the specific case of ADs, its Article 9 provides that: "Previously expressed wishes. The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account"[65]. Here, the expression "take into account" prompts reflection.

The Oviedo Convention, by emphasizing the importance of advance expressions of will, may, on the other hand, raise difficulties in the application of the document. Roberto Andorno explains that the aforementioned expression, without any further clarification, becomes ambiguous and may be interpreted in different ways. Therefore, "It would have been preferable to have clearer guidance for doctors as to what extent, or under what conditions, patients wishes expressed in advance must be implemented"[66]. In this sense, the author notes that "It is obvious that if health care professionals could arbitrarily decide, without giving any serious reason, not to comply with patients' preferences, the patient's effort of making an advance directive becomes useless".

In 2009, the Council of Europe published a new document on the subject, seeking to fill some of the identified gaps. Recommendation (2009)11 sets out principles relating to powers of attorney and advance directives in cases of incapacity[67]. It is divided into three parts: the first concerns its scope of application, the second addresses powers

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[64] According to Andorno, "The chief merit of the Council of Europe in this field consists in having obtained the ratification by a large number of European States of the first multilateral binding instrument entirely devoted to biomedical law". R. Andorno, The Oviedo Convention: a European legal framework at the intersection of human rights and health law. *JILB*, Vol. 02, 2005, p. 134.

[65] Available at: http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm. Accessed on April 30, 2026.

[66] R. Andorno, *Regulating advance directives at the Council of Europe*. In S. Negri, *Self-Determination, Dignity and End-of-Life Care*: regulating advance directives in international and comparative perspective. Leiden-Boston: Martinus Nijhoff Publishers, 2011, p. 77.

[67] "Recommendation (2009) 11 on principles concerning continuing powers of attorney and advance directives for incapacity". Available at: https://wcd.coe.int/ViewDoc.jsp?id=1563397&Site=CM. Accessed on April 30, 2026.

of attorney ("continuing powers of attorney"), and the third defines advance directives. The document begins by affirming and promoting self-determination, presenting it as a fundamental principle for capable adults who, in the event of future incapacity, may rely on instruments of that same self-determination, namely powers of attorney and advance directives[68]. It is interesting to note that, in the second part, the content concerning powers of attorney, in the so-called "principle 3," encompasses not only issues related to the health of the grantor of the power of attorney, but also economic and financial matters[69]. In the third part, concerning advance directives, "Principle 14" provides that they may apply to health, well-being and other personal situations, to economic and financial matters, and to the possible appointment of a guardian. It is for each State to determine whether advance directives will have binding effect. "Principle 15" states that those which do not have binding effect must be treated as expressions of will that are to be given due respect ("due respect").

Continuing the analysis regarding language and the consequences of its proper use, it can be observed that while Article 9 of the Oviedo Convention employs, in relation to the patient's wishes, the expression that they must be "taken into account" ("take into account"), Principle 15 of the Recommendation states that they must receive "due respect" ("due respect"). According to Roberto Andorno, this latter expression appears to carry greater force than the former. In this sense, the author notes that it is interesting that some countries use the verb "to respect" in their national legislation precisely to make advance directives binding. He illustrates this point through Article 372.2 of the Swiss Civil Code, which states that the advance directive must be respected by the physician, a term commonly interpreted as a prima facie recognition

[68] Principle 1 − Promotion of self-determination. 1. States should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives. 2. In accordance with the principles of self-determination and subsidiarity, states should consider giving those methods priority over other measures of protection.

[69] Principle 3 – Content. States should consider whether it should be possible for a continuing power of attorney to cover economic and financial matters, as well as health, welfare and other personal matters, and whether some particular matters should be excluded.

Principle 14 – Content. Advance directives may apply to health, welfare and other personal matters, to economic and financial matters, and to the choice of a guardian, should one be appointed.

Principle 15 – Effect. 1. States should decide to what extent advance directives should have binding effect. Advance directives which do not have binding effect should be treated as statements of wishes to be given due respect. 2. States should address the issue of situations that arise in the event of a substantial change in circumstances.

of the binding nature of advance directives (taking into account the existing legal system and whether they effectively reflect the patient's will)[70].

The diversity of terminology may lead to different interpretations of the subject in each country, it being emphasized that this diversity may also be related to the existence (or absence) of specific legislation on advance directives. In Spain, Law 41/2002 regulates patient autonomy and rights and obligations regarding information and clinical documentation[71]. In the Spanish framework, the legislation, in its Article 11, refers to "advance instructions" (*instrucciones previas*), which establish that a competent and free adult person may express their will in advance, with the aim that such will be respected at the time when the person is in a situation in which they are unable to express it personally. The Law also provides for the possibility of appointing a representative who will act as an interlocutor between the physician and the medical team in order to ensure compliance with the advance instructions[72]. These instructions must form part of the "clinical record" (*história clínica*)[73] of the patient and may be revoked at any time[74].

An important and legitimate step taken by the Spanish government concerns the so-called "National Registry of Advance Instructions", created by the "Ministry of Health and Consumer Affairs" (*Ministerio de Sanidad y Consumo*), in order to ensure the effectiveness of these instructions throughout the national territory. This system was established by Royal Decree 124/2007, which regulates the National Registry of

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[70]: R. Andorno, *Regulating advance directives at the Council of Europe*. In NEGRI, Stefania. *Self-Determination, Dignity and End-of-Life Care*: regulating advance directives in international and comparative perspective. Leiden-Boston: Martinus Nijhoff Publishers, 2011.

[71] Ley 41/2002, de 14 de noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica. Available at: http://www.boe.es, "Sede electrónica de la Agencia Estatal Boletín Oficial del Estado".

[72] "1. Por el documento de instrucciones previas, una persona mayor de edad, capaz y libre, manifiesta anticipadamente su voluntad, con objeto de que ésta se cumpla en el momento en que llegue a situaciones en cuyas circunstancias no sea capaz de expresarlos personalmente, sobre los cuidados y el tratamiento de su salud o, una vez llegado el fallecimiento, sobre el destino de su cuerpo o de los órganos del mismo. El otorgante del documento puede designar, además, un representante para que, llegado el caso, sirva como interlocutor suyo con el médico o el equipo sanitario para procurar el cumplimiento de las instrucciones previas".

[73] "3. No serán aplicadas las instrucciones previas contrarias al ordenamiento jurídico, a la 'lex artis', ni las que no se correspondan con el supuesto de hecho que el interesado haya previsto en el momento de manifestarlas. En la historia clínica del paciente quedará constancia razonada de las anotaciones relacionadas con estas previsiones".

[74] "4. Las instrucciones previas podrán revocarse libremente en cualquier momento dejando constancia por escrito".

"advance instructions" and the corresponding automated personal data file"[75], it provides, in Article 2, that "Registration in the National Registry of advance instructions ensures the effectiveness and enables knowledge throughout the national territory of the advance instructions granted by citizens who have formalized them in accordance with the provisions of the legislation of the Autonomous Communities." The document also states that the unit responsible for this Registry shall be in charge of adopting the necessary measures to guarantee the confidentiality, security, and integrity of the personal data contained therein.

Following the Iberian Peninsula, Portugal has also adopted specific legislation on the subject. Law No. 25/2012 provides, in its Article 1, that "This law establishes the legal framework for advance directives (ADs) in matters of health care, namely in the form of a living will (LV), regulates the appointment of a health care proxy, and creates the National Living Will Registry (RENTEV)"[76]. Persons who may issue an advance directive must, cumulatively, be of legal age, not be subject to interdiction or incapacitation due to mental disorder, and be capable of giving informed, free, and conscious consent. Article 5 specifies the limits of the document, considering legally non-existent and producing no effect any advance directives: (a) that are contrary to the law, public order, or that require actions contrary to good practice; (b) whose fulfillment may deliberately cause a non-natural and avoidable death, as provided for in Articles 134 and 135 of the Penal Code; (c) in which the grantor has not clearly and unequivocally expressed their will.

Portuguese law provides a specific provision regarding the possibility of appointing a so-called "health care proxy" in its Article 11, whereby any person may designate "a health care proxy, granting them representative powers to decide on the health care to be received, or not received, by the grantor, when the latter is unable to express their personal and autonomous will". Portuguese legislation clearly limits this mandate to "health care" only (excluding economic and financial matters, unlike the possibility provided in Council of Europe Recommendation (2009)11).

It is important to note that, similarly to Spanish legislation, Article 15 of the Portuguese law establishes the National Living Will Registry (RENTEV), with the purpose of "receiving, registering, organizing, and keeping updated, with regard to national citizens, foreign nationals, and stateless persons residing in Portugal, the

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[75] Available at: https://www.boe.es/buscar/pdf/2007/BOE-A-2007-3160-consolidado.pdf. Accessed on April 29, 2026.

[76] Legislation available at: https://dre.pt/pesquisa/-/search/179517/details/normal?q=Lei+n.%C2%BA%2025/2012+de+16+de+julho. Accessed on April 29, 2026.

information and documentation relating to the advance directive document and the health care proxy". The organization and functioning of RENTEV are regulated by the Government. As for the registration of advance directives and/or the health care proxy, the grantor may submit the respective document in person to RENTEV or send it by registered mail, in which case the grantor's signature must be duly authenticated.

In Latin America, reference can be made to Uruguay and to amendments to the Argentine Civil Code on this subject. In 2009, Law No. 18.473 on "Advance Will" (*Voluntad Anticipada*) was enacted in Uruguay. Its Article 1 establishes that any person of legal age, mentally competent, and acting voluntarily, consciously, and freely has the right to refuse medical treatments and procedures (except in cases where they affect or may affect the health of third parties)[77]. Article 2 provides that the advance expression of will shall be made in writing, signed by the individual and by witnesses, and may also be expressed in the presence of a public notary, being documented through a public deed or notarial record. It is important to emphasize that, in any of the forms in which it is executed, it must be incorporated into the patient's "clinical record"[78]. The law further provides that the following cannot act as witnesses: the physician, staff linked to the physician, or employees of the healthcare institution where the individual is a patient (Article 3). The "advance will" (*voluntad anticipada*) may be revoked at any time, either in writing or orally (Article 4). In cases where the patient has not expressed their wishes, the suspension of treatment shall be decided by the spouse or "partner" (*concubino*) or, in their absence, by first-degree relatives. Where there is disagreement among the aforementioned family members, unanimity will be required for the decision (Article 7).

An interesting difference in relation to other laws on the subject is that Uruguayan legislation establishes that, in all cases of treatment suspension covered by the law, the physician must report the matter to the institution's Bioethics Committee (when such committees exist), and the Committee must issue an opinion within 48 hours. If no opinion is issued within that period, the suspension of treatment is considered tacitly approved. Likewise, healthcare institutions must report all cases of treatment

[77] "Artículo1º.-Toda persona mayor de edad y psíquicamente apta, en forma voluntaria, consciente y libre, tiene derecho a oponerse a la aplicación de tratamientos y procedimientos médicos salvo que con ello afecte o pueda afectar la salud de terceros. (...)". Available at: https://legislativo.parlamento.gub.uy/temporales/leytemp997818.htm.

[78] "Artículo 2º. La expresión anticipada de la voluntad a que refiere el artículo anterior se realizará por escrito con la firma del titular y dos testigos. En caso de no poder firmar el titular, se hará por firma a ruego por parte de uno de los dos testigos. / También podrá manifestarse ante escribano público documentándose en escritura pública o acta notarial. / Cualquiera de las formas en que se consagre deberá ser incorporada a la historia clínica del paciente".

suspension to the "Comisión de Bioética y Calidad Integral de la Atención de la Salud del Ministerio de Salud Pública" (Article 8). Furthermore, Article 11 includes a "non-discrimination" clause, stating that public and private healthcare institutions may not condition the acceptance of a patient on whether or not they have an advance directive document[79]. Here, an important connection can be made with the principle of non-discrimination and non-stigmatization set out in the Universal Declaration on Bioethics and Human Rights (Article 11).

In Argentina, a new Civil Code was enacted in October 2014 and came into force in 2015[80]. In it, Article 60 addresses "advance medical directives" (*directivas médicas anticipadas*) with the following wording:

> The fully capable person may issue advance directives and grant a mandate regarding their health and in anticipation of their own incapacity. They may also designate the person or persons who are to express consent for medical acts and to exercise guardianship. Directives that imply the carrying out of euthanasia practices shall be considered as not written. This declaration of will may be freely revoked at any time by the person who made it.

As can be seen from a reading of this provision, there are important elements not addressed in its wording: for example, whether a specific form is required or whether there is a validity period for the document to be drawn up. Therefore, it may be necessary to enact specific legislation on the subject, given the gaps present in the aforementioned article.

The issue of end-of-life care and its connection with biomedical advances brings a new perspective to treatment and healing processes. Italy, a country that today has specific legislation on advance directives, began the debate on the subject through an initiative that started on social media. The case sparked broad social and political debate on the issue. An Italian association created an application on the social network Facebook to publicize the so-called "biological will" (*testamento biologico*)[81], referred to,

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[79] "Artículo 11. Las instituciones públicas y privadas de prestación de servicios de salud no condicionarán la aceptación del usuario ni lo discriminarán basándose en si éstos han documentado o no su voluntad anticipada".

[80] Código Civil y Comercial de la Nación. Available at: https://servicios.infoleg.gob.ar/infolegInternet/anexos/235000-239999/235975/texact.htm. Accessed on April 29, 2026.

[81] One of the terms commonly used in Italy to refer to advance directives before the enactment of specific legislation.

in this case, as "The Last Wish"[82]. Through this application, the social media user could designate two "testamentary executors", who would activate, in the event of the user's death, the publication of a message previously chosen by them to be posted on their profile. The service also allowed the sending of private messages to Facebook friends, as well as a final farewell to family members, and the biological will could be viewed by all members of the network. The creators of the service understood that the social network could serve as a means of publicizing and thus respecting the individual's choice regarding the medical treatment they wished to receive at the end of life. This choice was to be made while the person was fully conscious. The initiative also raised two issues: the creation of a so-called "post-mortem digital identity" on the internet and, additionally, it highlighted the risk of cases in which forms were filled out with incorrect user data, potentially spreading false news about a person's death.

In this sense, a delicate interface can be observed between the public and private spheres in the handling of personal and decisional data, as well as the rapid innovation of virtual practices, which prompts reflection on the validity of this type of public expression of will. The initiative to develop the application "The Last Wish" emerged in the wake of the media attention generated by the end-of-life debate in Italy. A particularly emblematic case brought this discussion to the forefront: Italian citizen Eluana Englaro suffered a serious car accident at the age of 21, remaining in a vegetative state for 17 years until the interruption of her artificial nutrition. The case went through multiple judicial instances, as Eluana's father claimed that she had expressed, on several occasions, her opposition to the artificial prolongation of life. The collection of testimonies from people close to Eluana was not sufficient to authorize the withdrawal of treatment, and the case, widely covered by the press, inflamed political debate in the country[83]. During the vote on a bill concerning artificial nutrition and hydration in the Italian Senate on February 9, 2009, Eluana passed away. The parliamentarians decided to withdraw the text from the agenda and

[82] News published in the newspaper *Corriere della Sera*, March 8th, 2011, available at: www.corriere.it.

[83] It is possible to find various news reports on the topic in the online editions of the Italian newspapers *Corriere della Sera* and *La Repubblica*, which have provided extensive coverage on the matter. Furthermore, there is a vast body of Italian legal and academic literature addressing this sensitive issue, among which: M. Sesta, Riflessioni sul testamento biologico. *Famiglia e Diritto*, 2008, 4, 407. T. Ballarino, Eutanasia e testamento biologico nel conflitto di leggi. *Rivista di Diritto Civile*, anno LIV, n. 1, gennaio-febbraio, 2008, pp. 69-85. S. Patti, La fine della vita e la dignità della morte. *Fam. Pers. Succ.*, 2006, 5, 390. A. Scalisi, Il diritto a morire: profili problematici. *Famiglia e Diritto*, 2009, 11, 1069. C. Tripodina, Il risvolto negativo del diritto alla salute: il diritto di rifiutare le cure. Studio in prospettiva comparata di due recenti casi italiani: il caso Welby e il caso Englaro. In R. Balduzzi, *Sistemi costituzionali, diritto alla salute e organizzazione sanitaria*: spunti e materiali per l'analisi comparata. Il Mulino, 2009.

transfer the debate to the document concerning the "biological will" (*testamento biologico*) and end-of-life cases.

It is interesting to note that many municipalities, due to the legal uncertainty raised at the time and the ideological clashes surrounding the case, began collecting written expressions of will from citizens who chose to proceed in this way. For example, the Municipality (*Comune*) of Massa, in Tuscany, developed a form of self-declaration replacing a notarial act for the submission of a biological will before a municipal official. However, these records were considered to have no legal effect by the Italian Ministers of Health, Welfare, and the Interior. It was understood that the collection of advance directives by municipalities was unlawful, as it concerned a matter falling within the State's legislative competence[84].

After several years of debate on the subject, Law No. 219 was enacted in 2017, entering into force in January 2018, and regulating "advance treatment provisions" (*disposizioni anticipate di trattamento* - DAT) in the country [85]. They may be made by adults and by persons capable of expressing their will and wishes. The document may be drafted in different ways, including through a notarial act or through the healthcare structures of each region that has regulated the DAT[86]. In cases where the patient is unable to draft the document, their will may be expressed through video recording or through devices that allow persons with disabilities to communicate. The document may be renewed, modified, or revoked at any time. The law also established that all advance treatment provisions (DAT) are to be entered into the "National DAT Database", instituted by the Italian Ministry of Health, which became operational on February 1, 2020.

6. Advance directives and Brazilian law

Having outlined some international aspects of advance directives (ADs), we now turn to the Brazilian context, specifically regarding the analysis of the applicability of CFM

[84] News published in the newspaper *La Repubblica* , November 19th, 2010, title "Il governo blocca il biotestamento - non validi i registri dei Comuni", available at: http://www.repubblica.it/cronaca/2010/11/19/news/biotestamento_circolari-9290090/.

[85] Legge 22 dicembre 2017, n. 219. Norme in materia di consenso informato e di disposizioni anticipate di trattamento. Available at: https://www.trovanorme.salute.gov.it/norme/dettaglioAtto?id=62663&completo=true. Accessed on April 29, 2026.

[86] Further and more detailed information is available on the Italian Ministry of Health website: salute.gov.it. Accessed on April 30.

Resolution No. 1.995/2012. To this end, a brief legal delimitation of the civil institute of the "will" (*testamento*) is first necessary, since it is from the idea of the civil will that the expression "living will" (*testamento vital)* has been used. The civil will is regulated by the Brazilian Civil Code of 2002. However, it is worth noting that in colonial Brazil, around the 18th century, wills were always drafted as a means of ensuring the expression of one's will in both patrimonial and non-patrimonial matters. Men and women, fearing an unexpected death, would take precautions in advance and seek a notary to record their decisions "regarding the reward of those who had assisted them in their illness and old age"[87].

At that time, the judicial system was still poorly structured, whether due to the absence of notary offices across the vast national territory or the difficulty of accessing the formal mechanisms established by the metropole. For this reason, people resorted to notaries. It was common practice to call a notary to record "the last wishes of those who were bedridden and fearing death"[88]. It is important to emphasize that the will was not only a privilege of the landowning elites: less privileged social groups at the time (such as women and enslaved people) also made use of wills, because they were relevant not only for the appointment of heirs and the distribution of assets, but also "for provisions regarding the funeral and care of the soul through the celebration of masses".

The will did not concern only patrimonial matters, but also, equally, non-patrimonial provisions. In testamentary dispositions, two types of concerns can be identified: first, "the expression of a strong religiosity that places above all the care of the soul, not only of the testator, but of all those to whom they were connected, including enslaved individuals themselves; second, the desire to protect the most vulnerable members of the family, namely female relatives such as daughters, granddaughters, and nieces"[89].

These indications demonstrate the importance of the possibility that each natural person has to freely dispose of their assets or make non-patrimonial decisions that will produce effects after death. Here, the principle of autonomy serves as a guiding framework for these matters, especially because autonomy recognizes and guarantees

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[87] Study on the historical perception of the civil will: M. B. Nizza da Silva, Vida privada e quotidiana no Brasil. *Apud* E. de O. Leite, *Comentários ao novo Código Civil*. Vol. XXI. Rio de Janeiro: Editora Forense, 2004, p. 300.

[88] Citations from this paragraph in: M. B. Nizza da Silva, Vida privada e quotidiana no Brasil. *Apud* E. de O. Leite, *Comentários ao novo Código Civil*. Vol. XXI. Rio de Janeiro: Editora Forense, 2004, pp. 300-301.

[89] M. B. Nizza da Silva, Vida privada e quotidiana no Brasil. *Apud* E. de O. Leite, *Comentários ao novo Código Civil*. Vol. XXI. Rio de Janeiro: Editora Forense, 2004, p. 301.

the existence of a private sphere of action for the individual, with normative effect[90]. It therefore becomes an important factor in the analysis of the drafting of an advance directive and its practical implications.

In the current context, Article 1.857 of the Brazilian Civil Code states that "Any legally capable person may dispose, by will, of all or part of their assets, to take effect after their death". Paragraph 2 of the same article provides that "Testamentary dispositions of a non-patrimonial nature are valid, even if the testator has limited themselves exclusively to such provisions". At this point, it is important to emphasize that the will has a *mortis causa* characteristic, meaning it produces effects only after the testator's death. Therefore, prior to that moment, it has no legal effect and does not bind the testator to the act, since the testator may freely revoke it, as established in Article 1.858 of the Civil Code: "A will is a strictly personal act and may be changed at any time".

Historically grounding the institute, definitions of the will already existed in Roman law that resemble the current understanding. For example, the jurist Modestinus stated: "a will is the lawful expression of our will regarding what we wish to be done after death". For Ulpian, also a jurist: "a will is the expression of last will made in a solemn form, to take effect after death". Furthermore, etymologically, *testamentum* derives from *testatio mentis*, that is, "a declaration of will"[91].

The essential characteristics of the will can also contribute to this reflection. A will is a legal transaction, because it involves an act performed by the *de cujus*—that is, the deceased—whose legal effects are those foreseen and intended by them, in accordance with the law; it is a highly personal legal act, because it is the disponor themselves who expresses the declaration of will; it is a unilateral act, since it involves a solitary and independent expression of will by the testator; it is a formal and solemn legal act, as it aims to provide greater guarantees, authenticity, and security to the testator's expression of will; it is a revocable legal act because, being an act of last will disposition, it remains, until the end, dependent on the testator's will; and finally, as noted above, it is a *mortis causa* legal act, because it only produces effects after the death of the testator.

This point must be reiterated and emphasized: while in the civil will we have dispositions that take effect after death, in advance directives we have dispositions

[90] F. dos S. Amaral Neto, Autonomia privada. *Revista do CEJ*: Centro de Estudos Judiciários, Brasília, n. 9, dezembro/99, p. 26.

[91] Informations and citations from this paragraph in: E. de O. Leite, *Comentários ao novo Código Civil*. Vol. XXI. Rio de Janeiro: Editora Forense, 2004, p. 306.

relating to acts prior to death. The person who chooses to document, in writing, their wishes regarding the treatment they want to receive in a state of unconsciousness expresses this will while alive. Therefore, and logically, not after death. This understanding is reflected in the drafting of laws regulating the conduct of healthcare professionals regarding the applicability of documents that attest to such wishes. The discussion on the possibility of legislating the creation of a document expressing a patient's will regarding the treatment to which they wish to be subjected in cases of manifest incapacity is part of the Brazilian context, which does not yet have specific legislation on the matter. Prior to the debate on advance directives, there is also the discussion on so-called orthothanasia, which has an important connection with the topic under analysis.

The Bill No. 6.715 of 2009, currently under consideration in the National Congress, provides for the amendment of the Brazilian Penal Code (CP) to exclude orthothanasia from criminal liability [92]. It proposes that the Penal Code be supplemented with Article 136-A, which states: "It does not constitute a crime, within the scope of palliative care provided to a terminal patient, to refrain from using disproportionate and extraordinary means in a situation of imminent and inevitable death, provided there is consent from the patient or, in their impossibility, from the spouse, partner, ascendant, descendant, or sibling".

The Brazilian Code of Medical Ethics also indicates the absence of unlawfulness in the practice of orthothanasia. In its Article 41, it provides that:

> It is prohibited for the physician to: (...) shorten the patient's life, even at the request of the patient or their legal representative. Sole paragraph: In cases of incurable and terminal illness, the physician must provide all available palliative care without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into account the expressed will of the patient or, in their impossibility, that of their legal representative[93].

The debate surrounding orthothanasia gained further prominence after the publication of CFM Resolution No. 1.805/2006, which, in its Article 1, provides: "It is permitted for the physician to limit or suspend procedures and treatments that prolong the life of a patient in the terminal phase of a serious and incurable illness,

[92] Monitoring of the legislative process of Projeto de Lei No 6.715, of 2009 in: https://www.camara.leg.br/proposicoesWeb/fichadetramitacao?idProposicao=465323. Accessed on April 30, 2026.

[93] Available at: https://portal.cfm.org.br/images/PDF/cem2019.pdf. Accessed on April 30, 2026.

respecting the will of the person or their legal representative". This Resolution was challenged in court through a public civil action filed by the Federal Public Prosecutor's Office (MPF) of the Federal District, which was ultimately dismissed by the Federal Court of the Federal District. The decision was based on the following arguments: (a) the Federal Council of Medicine (CFM) has the authority to issue Resolution No. 1.805/2006, as it does not concern criminal law but rather medical ethics and disciplinary consequences; (b) orthothanasia does not constitute the crime of homicide, when the Penal Code is interpreted in light of the Federal Constitution; and (c) the Resolution did not significantly alter the daily practice of physicians dealing with terminal patients, but instead encourages transparency by requiring physicians to clearly document which procedures are carried out and which are withheld.

Similar issues arose with the issuance of CFM Resolution No. 1.995/2012, which regulates advance directives. In January 2013, the Federal Public Prosecutor's Office of the state of Goiás filed a public civil action seeking a declaration of unconstitutionality and illegality of the Resolution. The arguments presented were that it: (a) exceeded the limits of regulatory authority; (b) posed risks to legal certainty, based on Article 5, caput and item XXXVI of the Federal Constitution; (c) excluded the family from decisions that would rightfully concern them, based on Article 226, caput, of the Constitution; and (d) established an inadequate instrument for recording patients' advance directives, on the grounds that medical records are not accessible to all, thereby creating a lack of oversight mechanisms regarding physicians' actions.

The Federal Court of Goiás, in turn, denied the preliminary injunction requested by the Federal Public Prosecutor's Office (MPF), on the grounds that: (a) the Federal Council of Medicine (CFM) did not exceed the regulatory powers granted by Law No. 3.268/57[94], The court held that: (a) the Resolution merely regulates ethical medical conduct in the factual situation in which a patient expresses their will regarding the care and treatments they wish, or do not wish, to receive; (b) the Resolution is constitutional and aligned with the principle of human dignity, as it ensures that terminal patients receive palliative care and are not subjected, against their will, to treatments that prolong suffering without providing any benefit; and (c) the patient's expression of will is free, based on Article 107 of the Civil Code[95]; (d) for the validity

[94] "Regulates the Medical Councils and provides for other matters.". Available at: http://www.planalto.gov.br/ccivil_03/Leis/L3268.htm. Accessed on April 30, 2026.

[95] Article 107. The validity of a declaration of will shall not depend on any special form, unless the law expressly requires it.

of advance directives, the requirements set out in Article 104 of the Civil Code apply[96]; therefore, it is not necessary for the Resolution to restate what is already provided by law.

There is also a debate that can be established between the civil and criminal spheres regarding the application of Article 15 of the Civil Code and Article 146, paragraph 3, item I, of the Penal Code. Article 15 of the Civil Code provides that "No one may be compelled to undergo medical treatment or surgical intervention when there is a risk to life". However, the wording of this provision may lead to the interpretation that there would be an obligation to accept treatment or surgery when there is no risk to life[97], which would contradict the ethical and legal framework previously outlined. Article 146, paragraph 3, item I, of the Penal Code provides that:

> Article 146 - "To constrain someone, by means of violence or serious threat, or after having reduced, by any other means, their capacity for resistance, not to do what the law permits, or to do what it does not command: Penalty — detention, from three months to one year, or a fine. (…) § 3 — The following are not included within the scope of this article: I — medical or surgical intervention, without the consent of the patient or their legal representative, if justified by imminent danger to life.

Within the framework analyzed, there is a clear indication that the patient's private autonomy should prevail. Under this understanding, "by forcibly imposing a curative measure expressly not authorized by an adult who is sufficiently informed, the physician would be committing the crime of unlawful coercion"[98].A fundamental issue for the future implementation of ADs in Brazil concerns an important observation made by the author: that "Another consequence lies in the fact that a physician's omission, when refraining from imposing treatment that has not been authorized by the patient, even if medically necessary, is not classified as the crime of failure to provide assistance".

In this regard, it is appropriate to highlight the distinction between the following terms: orthothanasia is characterized by respect for the decision of a patient in the

[96] Article 104. The validity of a legal transaction requires: I – a legally capable agent; II – a lawful, possible, determined or determinable object; III – a form prescribed or not prohibited by law.

[97] D. C. Ribeiro, Autonomia: viver a própria vida e morrer a própria morte. *Cad. Saúde Pública*, Rio de Janeiro, 22 (8): 1749-1754, ago, 2006.

[98] M. Reale Júnior, *Direito penal*: jurisprudência em debate, crimes contra a pessoa, volume 1. Miguel Reale Júnior, Janaína Conceição Paschoal; coordenador Miguel Reale Júnior. Rio de Janeiro: GZ Ed., 2011, p. 188.

terminal stage of a serious and incurable illness to limit or suspend procedures and treatments that prolong life, while still ensuring all necessary palliative and comprehensive care. In turn, advance directives concern a decision made prior to the onset of illness, to be applied in situations where, once the illness occurs or is established, the patient is in a state of unconsciousness and unable to express their will freely and autonomously. It is essential not to confuse these situations—both of which promote and give effect to patient autonomy, beneficence in treatment, and medical ethics—with euthanasia, which involves intentionally inducing death, with the conscious authorization of the person, in order to end suffering - not necessarily limited to terminal conditions. In Brazil, this practice is not permitted[99].

In a recent legislative movement, there is a bill under consideration aimed at amending the current Civil Code, which includes a provision on advance directives. However, it is argued that this is not the most appropriate path for debating and defining the issue, given the complexity involved[100]. Current studies on the subject indicate that, from a legal perspective within the Brazilian legal system, advance directives are characterized as unilateral legal transactions, of a highly personal nature and existential content, requiring compliance with the essential elements of validity, such as a legally capable agent and a lawful and possible object. It is also emphasized that the possible absence of specific legislation does not compromise the validity of advance directives—although the creation of regulatory mechanisms to systematize the institute would be important[101].

A significant step forward in this field can be found in Law No. 15.378 of 2026, known as the *Patient Rights Statute*[102]. The Statute is "intended to regulate the rights and responsibilities of patients receiving care from health services of any nature or from healthcare professionals". Article 2(II) defines advance directives as a "written declaration of will regarding the care, procedures, and treatments that the patient accepts or refuses, which must be respected when the patient is unable to express his or her wishes freely and autonomously". The Statute guarantees respect for advance

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[99] C. Avancini Alves, Eutanásia em discussão. *Jornal Zero Hora*, 06 de março de 2013, p. 15.

[100] Further analysis of this debate in: C. Avancini Alves, *A Reforma do Código Civil e a Impossibilidade de um "Direito dos Mortos". In*: J. Martins-Costa; F. Martins; M. C. Craveiro; R. B. Xavier (Orgs.) *Boletim IDiP-IEC*, vol. LXIII. Published on July 23, 2025. Available at: https://canalarbitragem.com.br/boletim-idip-iec/63-a-reforma-do-codigo-civil-e-a-impossibilidade-de-um-direito-dos-mortos/

[101] R. B. Garbin, *Diretivas antecipadas de fim de vida*: fundamentos constitucionais e análise jurídica. Porto Alegre, RS: Dialogar Editora, 2026, pp. 258-259.

[102] Available at: https://www2.camara.leg.br/legin/fed/lei/2026/lei-15378-6-abril-2026-798918-publicacaooriginal-178753-pl.html.. Accessed on May 27, 2026.

directives even in the situations provided for in Article 14, which establishes that patients have the right to informed consent free from coercion or undue influence, except in life-threatening situations in which they are unconscious. Paragraph 1 further states that "The patient has the right to withdraw consent at any time without suffering reprisals".

Article 20 provides that "The patient has the right to have his or her advance directives respected by family members and healthcare professionals". In the context of patient responsibilities, Article 22(III) states that it is the patient's responsibility to "ensure that the healthcare institution keeps a copy of his or her written advance directives, if any exist". Particular attention should be given to Article 24, which states: "The violation of the patient rights established in this Law shall be characterized as a situation contrary to human rights, pursuant to Law No. 12.986 of June 2, 2014". Law No. 12.986/2014 governs the National Human Rights Council (CNDH), whose purpose is to promote and protect human rights through preventive, protective, remedial, and sanctioning actions addressing conduct and situations that threaten or violate such rights.

In this sense, because advance directives are incorporated into the *Patient Rights Statute*, they are encompassed within the legal framework of human rights. Consequently, the violation of advance directives, as patient rights, constitutes a situation contrary to human rights under the law. This framework further underscores the importance of enacting specific legislation on the subject.

It is therefore suggested that the following points be considered in the process of drafting legislation on ADs in Brazil:

a) In defining advance directives, it is important to determine whether the scope of expression will be restricted or expanded. The CFM Resolution No. 1.995/2012 refers to ADs as "the set of wishes previously and expressly manifested by the patient", whereas Law No. 15.378/2026 describes them as a "written declaration of will". In this regard, broader alternatives may be beneficial (for example, where it is impossible to reduce the patient's wishes to writing). However, the advancement of new technologies, especially artificial intelligence and audiovisual manipulation, must also be taken into account.

b) The above consideration arises in light of Brazil's vast territorial dimensions and the differing levels of access to healthcare, which are reflected in another issue: the communication and interoperability of institutions regarding advance directives. Law No. 15.378/2026 assigns to patients the responsibility of ensuring that healthcare institutions retain a written copy of their advance directives, if such directives exist (Art. 22(III)). In turn, CFM Resolution No. 1.995/2012 provides that "The physician

shall record in the medical record any advance directives directly communicated by the patient" (Art. 2, §4). Specific legislation could be informed by studies examining the feasibility of connecting healthcare institutions, as has been done in countries discussed in this article, thereby enhancing both legal certainty and social security with respect to these expressions of will. Such a framework would appropriately balance private and public interests: the privacy of decisions concerning ADs on the one hand, and the institutional character of healthcare as a public and social right guaranteed by the Federal Constitution (Art. 6) on the other.

c) The possibility of modifying ADs at any time is widely recognized. Specific legislation should therefore establish their duration and clarify the legal effects of any applicable time limits.

d) Both CFM Resolution No. 1.995/2012 and Law No. 15.378/2026 address the appointment of a representative. The Resolution provides that, if designated by the patient, information supplied by the representative "shall be taken into consideration by the physician" (Art. 2, §1). Article 6 of the Law states that "the patient has the right to freely appoint a representative at any time during healthcare treatment, by means of an entry in the medical record". Furthermore, Article 2(III) defines a representative as a "person designated by the patient, in his or her advance directives or in any other written record, to make decisions regarding healthcare on the patient's behalf when the patient is unable to express his or her wishes freely and autonomously". The development of specific legislation should establish the form, scope, and limits of such designation to ensure effective communication among all parties involved. Current instruments, for example, provide for the appointment of a representative but do not address whether that individual has been informed of or has accepted the role.

e) An important feature that should be retained, and which is already addressed in CFM Resolution No. 1.995/2012, concerns Bioethics Committees. Article 2, §5 provides that when the patient's advance directives are unknown, no representative has been designated, no family members are available, or there is a lack of consensus among them, "the physician shall seek guidance from the institution's Bioethics Committee, if one exists, or, in its absence, from the hospital's Medical Ethics Committee or the Regional or Federal Council of Medicine, to support decision-making regarding ethical conflicts whenever such a measure is deemed necessary and appropriate." This framework may, where appropriate, be connected to the National Human Rights Council in matters falling within its jurisdiction.

f) Specific legislation on ADs should integrate important legal fields, namely constitutional law, civil law, and criminal law, with particular regard to human dignity, legal capacity and autonomy, and the non-criminalization of physicians' omissions in

respecting patient decisions. Beyond the numerous issues already discussed throughout this article concerning these three—and other—legal spheres, which are by no means exhausted here, attention should be drawn to the interconnected and cross-cutting nature of ADs and the legal coordination required for their effective implementation.

In this context, the drafting of specific legislation regulating advance directives raises two considerations: on the one hand, such a law would provide legal protection for physicians and healthcare staff regarding the implementation of patients' advance directives; on the other hand, there is the importance of a carefully drafted law, attentive and sensitive to the clinical context, so that it may serve as an effective guideline for legal and social action. The topic requires a thorough examination of language use and its practical application in concrete cases, so that any potential legislation introduces meaningful elements into the decision-making process rather than rigidifying practice at a moment that demands clarity in interpretation and application of the document.

7. Concluding remarks

In concluding remarks on the subject—though without exhausting its complexity—it is argued that reflection on end-of-life issues confronts us, in a very direct way, with our own humanity. The Italian jurist Stefano Rodotà states that the contours of suffering or pain are not only physical but also sociocultural; for this reason, pain cannot be fully captured by formal legal categories, although Law does not cease to follow it. This is because, if medical technology can lead to so-called "*accanimento terapeutico*," that is, therapeutic obstinacy in the maintenance of life at any cost, the legal sphere has sought to understand and consider whether it is possible to speak of a "right to die with dignity"[103]. According to him, this involves a perspective to be directed toward palliative care, which seeks to establish a balance between the reduction of pain and the reduction (rather than the interruption) of life[104].

This perspective is extended to the scope of advance directives. Their implementation is consistent with the recognition of patient autonomy. Such autonomy, at no point,

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[103] S. Rodotà, *La vita e le regole*: tra diritto e non diritto. Milano: Feltrinelli Editore, 2006, p. 212.

[104] According to Rodotà, "The right to die with dignity is not limited to rejecting therapeutic obstinacy, but also involves the pursuit of any form of care that can alleviate pain, even if such pursuit may reduce life expectancy". S. Rodotà,. *La vita e le regole*: tra diritto e non diritto. Milano: Feltrinelli Editore, 2006, p. 213.

removes or negates the autonomy of the physician. The European context highlights self-determination as a foundational element in the formulation of advance directives, a factor that connects with the Brazilian scenario insofar as CFM Resolution No. 1.995/2012 seeks to "recognize the alterity present in this relationship, where decisions must be shared. From individual responsibility, within this perspective of sharing, arises the notion of co-responsibility. There is no subordination, but rather mutual recognition of an ethical co-presence in the physician–patient relationship"[105]. The recent Law No. 15.378/2026, by incorporating advance directives as part of patients' rights and establishing that violations of those rights constitute situations contrary to human rights, strengthens the protection of individual autonomy and human dignity.

It is important, always and consistently, to associate and recall the continuity of our existence, insofar as the expression of our previously manifested will cannot simply be excluded from our history or, in the words of Giovanni Maria Flick, from our "historicized will" (*volontà storicizzata*) According to this Italian jurist, it is not possible "to accept the idea that a subject, deprived of their capacity for self-determination, becomes an 'object'; that they are no longer recognized as having the possibility to continue asserting—within the limits of the new situation—the self-determination previously expressed"[106].

This scenario enables a more comprehensive view of patient care and brings forward the reflection on what I call the "temporality factor" (already mentioned at the beginning of this section), that is, the possibility of change, at any moment, of advance directives, due to a new personal position regarding a given treatment or circumstance that alters one's perception of end-of-life situations; and, in cases of the patient's manifest incapacity, their representative may adopt this perspective in order to consider, for example, the discovery of new treatment during the decision-making process that may bring effective benefits to the patient. Through this balance between autonomy and beneficence, the aim is to achieve shared decision-making and appropriate treatment for the patient in accordance with their clinical condition, integrating and connecting bioethical and legal elements in the analysis of the concrete case.

Using the term "living will" (*testamento vital*) in the Brazilian context therefore requires proper contextualization, insofar as *testament* refers to dispositions to be executed after

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[105] C. Avancini Alves; M. S. Fernandes; J. R. Goldim, Diretivas antecipadas de vontade*:* um novo desafio para a relação médico-paciente. *Revista HCPA*. 2012;32(3):358-362.

[106] G. M. Flick, A proposito di testamento biologico: spunti per una discussione. *Politica del Diritto*, anno XL, n. 4, dicembre 2009, p. 526.

death, while *vital* relates to life, its preservation, and its essential nature: if the term is simply presented without reflection, it may not be adequately understood as an autonomous and free expression of will, especially regarding treatment or decision-making to be carried out in and for life. This is because "research into how the language we speak shapes the way we think has helped uncover how we create knowledge, construct reality, and use our intelligence—helping us understand precisely the essence of what makes us human"[107].

The enactment of specific legislation on advance directives, with due attention to its language, the meanings embedded within it, and the broad economic, social, and cultural issues involved in its design, may contribute significantly to their effective implementation in Brazil. The combination of the bioethical principle of beneficence, the principle of autonomy, and the principle of human dignity creates a common link among legal systems that affirm the human person as a "value-source" (*valor-fonte*)"[108] of their social formation, in its totality and complexity.

[107] L. Boroditsky, Como a linguagem modela o pensamento. *Scientific American/Mente Cérebro*, Ano XIX, nº 247, Agosto 2013, p. 35.

[108] Expression of Miguel Reale: M. Reale, *Pluralismo e liberdade*. São Paulo: Edição Saraiva, 1963, p. 74.

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