

Advance Directive: historical course in Latin America

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Abstract

Advance directives are instruments to guarantee the patient the right to decide about their health care, especially those related to the end of life. In this article, through an integrative review of the literature conducted between December 2017 and January 2018, the objective was to understand the use of this instrument and to trace its historical course in Latin American countries that already have a consolidated legislation, such as Puerto Rico, Argentina, México, Uruguay and Colombia. In Brazil, since there is still no law on the subject, the directives are treated and discussed through Resolution 1995/2012 of the Federal Council of Medicine, which may generate legal uncertainty in those involved. It was observed, as a common feature in the countries studied, difficulty in the dissemination and use of this resource.

Keywords: Advance directives. Right to die. Bioethics. Personal autonomy. Latin America.

Resumo

Diretivas antecipadas de vontade: percurso histórico na América Latina

As diretivas antecipadas de vontade são instrumento para garantir ao paciente o direito de decidir sobre seus cuidados de saúde, especialmente os relacionados ao fim da vida. Neste artigo, por meio de revisão integrativa da literatura realizada entre dezembro de 2017 e janeiro de 2018, objetivou-se compreender o uso desse instrumento e traçar seu percurso histórico nos países da América Latina que já têm legislação consolidada, como Porto Rico, Argentina, México, Uruguai e Colômbia. No Brasil, como ainda não há lei sobre o tema, as diretivas são tratadas e discutidas pela Resolução 1.995/2012 do Conselho Federal de Medicina, o que pode gerar insegurança jurídica nos envolvidos. Observou-se, como característica comum nos países estudados, dificuldade quanto à divulgação e utilização desse recurso.

Palavras-chave: Diretivas antecipadas. Direito a morrer. Bioética. Autonomia pessoal. América Latina.

Resumen

Directivas anticipadas de voluntad: recorrido histórico en América Latina

Las directivas anticipadas de voluntad constituyen un instrumento para garantizar al paciente el derecho a decidir sobre sus cuidados de salud, especialmente los relacionados con el fin de la vida. En este artículo, a través de una revisión integrativa de la literatura, realizada entre diciembre de 2017 y enero de 2018, se tuvo como objetivo comprender la utilización de este instrumento y trazar un recorrido histórico en los países de América Latina que ya poseen una legislación consolidada, como Puerto Rico, Argentina, México, Uruguay y Colombia. En Brasil, como aún no hay una ley sobre el tema, las directivas son tratadas y discutidas por la Resolución 1.995/2012 del Consejo Federal de Medicina, lo que puede generar inseguridad jurídica para los involucrados. Se observó, como característica común en los países estudiados, una dificultad en la divulgación y la utilización de este recurso.

Palabras clave: Directivas anticipadas. Derecho a morir. Bioética. Autonomía personal. América Latina.

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Declaram não haver conflito de interesse.

Throughout history, death has often been a subject of concern and source of distress for humanity. Recognized as the only certainty of life and thought over popularly as its antagonist, death and the process of dying are social phenomena experienced *in different ways, based on the meaning shared through this experience*¹.

Ariès observes how the traditional model of death that once consisted of a natural and familiar occurrence, publicly shared by other members of the surrounding community at people's residences, has become, in the twentieth century, the modern model of death, which is now perceived as *inconvenient and dirty*². The process of dying has been transferred to hospitals *where medicine has produced an unconscious, silent, hidden, medically monitored and controlled death thanks to the development of resources capable of maintaining and extending life*³. The dying individual has been deprived from taking control over the process, since health professionals are in charge of managing schedules, procedures and interventions.

In the biomedical field, *the relationship among health professionals (knowledge holders) and patients (disease carriers) used to be quite asymmetric*⁴. However, it has been slowly changing over the course of the 20th and 21st centuries. Sick people are no longer mere patients or objects of care; they have taken on a much more predominant role in their relationship with health professionals regarding procedures, interventions and treatment alternatives. This change reflects the development of the patient's autonomy but it does not mean a transfer of decision-making responsibilities⁵. It is a listening exercise during which health professionals have a chance to understand their patients' needs. Thus, it becomes necessary *to place patients back in the center of the process, focusing on their dignity and autonomy*⁶.

In this sense, advance healthcare directives arise (AHD) *in response to technological advances and aggressive medical treatment applied to ambiguous situations, such as poor prognosis*⁷. For Bussinguer and Barcellos, *the right patients have to express in advance how they wish to live their last moments has the power to restore their dignity and autonomy*⁸.

AHD are written by a lucid person, capable of exercising his/her right to make choices, and aware of the decisions that are being made, as well as their consequences. They must describe the patient's preferences for the type of care, treatment and interventions to which it wishes (or not), when unable to express him/herself. Patients reserve the right to revoke such directives anytime. If they decide not to

do so, the directives will come into force when they become unable to make their own decisions^{9,10}.

Technically, there are two kinds of directives: *durable power of attorney for health and living will*. This division was established by the Patient Self-Determination Act (PSDA)¹¹, a legislation that ensures, communicates and protects the patient's right to self-determination in health care decisions. However, one modality does not exclude the other, and there is still the possibility of both coexisting in a single document¹².

The durable power of attorney appoints a health assignee and describes the breadth of his/her powers. In certain countries, the law allows the assignee to be responsible for decisions when the patient is permanently or temporarily unable to do so⁹; in others, the assignee acts as a guardian of the patient's will, ensuring that the document is fulfilled exactly as written.

This type of directive fits into the substitute judgment model, which assumes that *the intimacy between the surrogate decision-maker and the patient is profound and relevant enough so that the final decision truly reflects the patient's goals and opinions*¹³. The biggest challenge is to select an assignee, considering that the relationship between the parties is reliable enough so that the person chosen knows exactly what the patient's decision would be without imposing his/her own will. Thus, those who could be considered impartial – non-acquaintances, hospital staff, or judges must be ruled out. It is recommended that a family member or a close friend is chosen as an assignee, which, however, may lead to another issue, since the degree of affection between the parties can hinder the decision-making process.

On the other hand, the living will *grants the assignee the right to suspend treatment when the grantor is no longer able to make decisions for him/herself due to a terminal state, a persistent vegetative state or a chronic incurable disease*¹⁴. This document fits into the model of pure autonomy as it puts into effect the patient's will and prevents practices of therapeutic obstinacy, determining the acceptance or refusal of interventions¹⁵.

The integrative review of this work included research on the descriptors "living will" and "advance directives" in English, Portuguese and Spanish at the Biblioteca Virtual em Saúde - BVS (Virtual Health Library). The initial research revealed 51 articles, 16 of which were selected^{10,16-30}. The Latin American and Caribbean Health Sciences (Lilacs)¹⁰, the Scientific Electronic Library Online (SciELO)¹⁶⁻¹⁸, Medical Literature Analysis and Retrieval System (Medline)¹⁹⁻²⁶, as well as Índice Bibliográfico Español en Ciencias de la Salud - Ibesc

(Spanish Bibliographic Health Sciences Index)²⁷⁻³⁰ (Table 1) database were used for the preparation of this research. Official websites were assessed

in order to gather data on the advance healthcare directive legislation adopted in the countries analyzed in this study.

Table 1. Body of study

Basis	Authors	Title of the article	Magazine
Medline (n=8)	Grinberg M, Chehaibar GZ ¹⁹	Testamento vital	Arq Bras Cardiol. 2012;99(6):1166.
	Alfonso H ²⁰	The importance of living wills and advance directives	J Gerontol Nurs. 2009;35(10):42-5.
	Allen SL, Davis KS, Rousseau PC, Iverson PJ, Mauldin PD, Moran WP ²¹	Advanced care directives: overcoming the obstacles	J Grad Med Educ. 2015;7(1):91-4.
	Muller LS ²²	Polst: something new has been added	Prof Case Manag. 2012;17(2):90-3.
	Mitchell M ²³	An analysis of common arguments against advance directives	Nurs Ethics. 2012;19(2):245-51.
	White DB, Arnold RM ²⁴	The evolution of advance directives	Jama. 2011;306(3):1485-6.
	Silveira MJ, Kim SYH, Langa KM ²⁵	Advance directives and outcomes of surrogate decision making before death	N Engl J Med. 2010;362:1211-8.
	Shaw D ²⁶	A direct advance on advance directives	Bioethics. 2012; 26(5):267-74.
Ibecs (n=4)	Nebot C, Ortega B, Joaquín Mira J, Ortiz L ²⁷	Morir con dignidad: estudio sobre voluntades anticipadas	Gac Sanit. 2010; 24(6):437-45.
	Pezzano LC ²⁸	Directivas anticipadas en el ámbito de la salud: evolución y situación actual	Rev Hosp Ital B Aires. 2013;33(1):18-22.
	Cantú G, Alberú J ²⁹	Ley de la voluntad anticipada en México	Nefrología. 2013;33(1):142-3.
	Martinez S, Lima A ³⁰	O testamento vital e a relação médico-paciente na perspectiva da autonomia privada e da dignidade da pessoa humana	Rev Bioét Derecho. 2016;37:103-20.
SciELO (n=3)	Dadalto L ¹⁶	Reflexos jurídicos da Resolução CFM 1.995/12	Rev. bioét. (Impr.). 2013;21(1):106-12.
	Nunes MI, Fabri MA ¹⁷	Directivas antecipadas de vontade: benefícios, obstáculos e limites	Rev. bioét. (Impr.). 2014;22(2):241-51.
	Dadalto L, Tupinambás U, Greco DB ¹⁸	Directivas antecipadas de vontade: um modelo brasileiro	Rev. bioét. (Impr.). 2013;21(3):463-76.
Lilacs (n=1)	Bussinguer ECA, Barcellos IA ¹⁰	O direito de viver a própria morte e sua constitucionalidade	Ciênc Saúde Coletiva. 2013;18(9):2691-8.

The origin of the advance healthcare directives

The idea of a document recording the will of a person was born in 1967, in the United States, being initially proposed by the Euthanasia Society of America (ESA)³¹. Although ESA had previously used the expression "living will", lawyer Luis Kutner³², proposed in 1969 his premises and the model of the document in his work entitled "Due process of euthanasia: the living will, a proposal" In his work, the author considers legitimate, as an integral part of the right to privacy, the refusal of treatment that

extends the life of the patient before an incurable and irreversible scenario.

The subject resurfaced in the 1970s with the case of Karen Ann Quinlan case, who was diagnosed with irreversible coma at age 22. Her parents asked for the withdrawal of life support, claiming that Karen had told them that she no longer wished to be kept alive by machines. The issue reached the Supreme Court, which requested the opinion of the hospital's ethics committee, created especially to meet the request. The committee confirmed that Ms. Quilan's situation was irreversible and its verdict was favorable to the withdrawal of the devices. After that, she

survived for nine years without ever moving from a vegetative state³³. The debate questioned whether the expression of will outside the context of the disease could be taken into account for decision-making.

In August 1976, amidst the discussions on the case, the State of California, through the *Natural Death Act*³⁴, granted individuals the right to refuse or suspend medical treatment. This law also protected the health professional from prosecution for respecting the patient's will. For Pona¹², the California law was the first legislative resource to regulate natural death, ensuring those dying the right to die.

Following this law, members of medical associations met and produced a guide that included rules on how to: 1) seek help to write the document; 2) request that this record be part of the clinical history; 3) ensure that it is done in freely; and 4) determine that it remains valid for five years. Witnesses are required⁹ and their selection follows strict criteria. If the document is prepared in the hospital, no employee, doctor or anyone working with directly with them can testify. Patient and witness cannot be relatives; the latter cannot benefit in any way from the death of the patient. Other requirements determine that the patient is of legal age and not pregnant.

Physicians must comply with the document and check its validity, in addition to requesting the declaration of another physician confirming that the patient's condition is terminal. Also, the guide states that the patient must have been aware of his/her condition for at least 15 days. In general, these provisions have been included in the advance healthcare directives of several countries.

In 1977, seven US states legally recognized the validity of the document and similar laws have been introduced to 42 states ever since³⁵. In 1983, the *California's Durable Power of Attorney for Health Care Act*³⁶, which established the long-term mandate, recognizing the right of the patient to appoint an assignee to make decisions own his/her behalf if no longer able to do so.

The need to regulate situations that required decision-making from individuals unable to make their own decisions led the United States to approve, in 1990, the PSDA¹¹, which is the first federal law that ensures the patient's right to self-determination in health care decisions³⁷. As a federal law, it aims to inform the public about the directives and to encourage their use, proposing to resolve ethical conflicts derived from the withdrawal or absence of treatment for irreversible situations¹². On the other hand, Emanuel and Emanuel³⁵ claim that the PSDA

is only a guideline, and many important issues, such as the concept of terminal patient, are dealt with differently in each state.

Since the PSDA came into force, hospitals, nursing homes and asylums have been asked to prepare guidelines on early declarations. In addition, health professionals must be able to address such issues at the time of admission and advise patients of their right to draft a similar document if they have not done so yet²⁸.

Extensive research on Advance Healthcare Directives was carried out during the implementation phase of the PSDA, such as the "*Study to understand prognoses and preferences for outcomes and risks of treatments*" (support)³⁸. This study, conducted with 9,105 hospitalized patients between 1989 and 1994, was divided into two phases, one descriptive and one interventional. Their results exposed the need to broaden the perception about the theme: instead of prioritizing documents, the communicative processes among professionals, family members and patients must be favored to improve the moral quality of decisions at the end of life³⁹.

The *advance care planning*⁴⁰ arises as a medical care planning process when patients lose their decision-making capacity. It aims to discuss and help patients to clarify their personal values and goals about health and medical treatment. According to Pezzano²⁸, the directives consist of an important tool to improve communication.

Despite their benefits, between 2011 and 2016, the proportion of adults whose treatment included the advanced directives established in the United States was still 36.7%, a very unsatisfactory number⁴¹. Several reasons may explain the low adherence rate: lack of knowledge, poor interaction between physician and patient, lack of a system that enables patients to register their will, and uncertainty about the will in the event of a fatal diagnosis⁴².

The discussions are well established in the United States despite of the data provided, and there are other types of devices capable of ensuring that the patient's wishes are fulfilled. The *advance medical care directive*⁴³, a form completed after discussion with the medical team; the *value history*⁴⁴, which records the patient's history and values that will substantiate the decision-making process; the *combined directive*⁴⁵, which describes patient values and nominates the assignee; and the *Physician Orders for Life-Sustaining Treatment* (Polst)⁴⁶, a form filled out by the physician describing treatment alternatives following the interview with the patient.

Inaccurate terminology

The AHD have received different denominations — translated or transposed, such as *living will*, biological will, advance declaration of will, previous declaration of will of the terminal patient, and anticipated wishes. The terms often generate misunderstandings about the concept behind the Advance Healthcare Directives, especially living will and long-term mandate. In Brazil, living will is the most used nomenclature.

The *living will* is a document through which patients express their wishes *in relation to the treatments and medical care they wish or not to receive in situations when they are unable to express their own will, temporarily or permanently, whether or not in a terminally-ill situation*⁴⁷. It should be noted that the word “will” was a bad and imprecise translation choice for *living will*^{48,49}.

In the field of law, the validity of the use of this word is often questioned, since “will” carries a juridical, unilateral, personal, free, solemn and revocable meaning applicable to a postmortem scenario⁵⁰. *It is also use in other legal snot necessarily related to the division of assets*⁵¹. Therefore, a living will is similar to a will because it is also a legal, unilateral, and personal document that is revocable at any time. Both documents are structurally different but they may be used for similar purposes, when it is considered that *will is the disposition of someone’s last wishes*⁵².

Despite all the discussion present in the literature, “living will” is the most used expression to register the wishes of the terminally ill”. It is important to note that this document can legally grant doctors the right to make decisions during conflicting situations. It also enables patients to exercise self-governance and autonomy, helping the communication among family members, the health team and patients, as it requires a deeper reflection on fear, illness, treatment alternatives and death. Advance Healthcare Directives prepared as a *living will* must not be understood as a list of consent for or refusal to certain treatments that do not correspond to the real needs of the patient⁴⁹, but as an instrument that ensures a dignified death.

Criticism of advance healthcare directives

Advance Healthcare Directives, particularly living wills, are widely criticized. Its opponents often seem to believe that the document, rather than

providing a dignified death, is used as a subterfuge to legalize euthanasia¹⁶. Bermejo and Belda point out *that the expression “dignified death” has been rejected, perhaps misinterpreted because it was directly related to euthanasia as if it was an open door to think about it*⁵³, which definitely does not correspond to the truth. It is important to highlight that euthanasia is prohibited in most countries that have legalized the living will. In addition, there are lawful means in place that prohibit the execution of a directive in any way contrary to the legal system. Even in the case of the Netherlands and Belgium, where euthanasia is allowed, the models of the document and its rules differ from those applied to the living will.

Another criticism refers to the authenticity and stability of the decision. The document is elaborated based on what life would be like in a condition never experienced and by someone whose perception could change when the hypothesis became reality^{17,49}. To circumvent this criticism, the document may be revoked at any time while the patient is capable of making decisions.

The connection between the document and the rapid development of medicine, which could refute or delay the treatment provided in the directive, is also questioned. This criticism can be countered by the fact that measures contrary to good medical practice are not applied. This topic, however, appears to be susceptible to the discussion of what would effectively constitute good practice⁵⁴.

The preparation of an AHD *is an ethical act that encompasses great responsibility*⁵⁵. It is a time when the individual can make very personal decisions, free from the external interference of family members, doctors or the institution⁵⁶. Based on the concept of responsibility, freedom and dignity, the preparation of an AHD is perhaps a way to democratize the power of decision-making in an environment where these decisions are increasingly complex and ethically, legally and emotionally compromising.

Advance healthcare directives in Latin America

AHD laws were enacted in Puerto Rico, Argentina, Mexico, Uruguay, and Colombia. In Brazil, there is no legislation on the subject, only a resolution issued by the Conselho Federal de Medicina - CFM (Federal Council of Medicine).

Puerto Rico

Puerto Rico was the first Latin American country to regulate the prior declaration of will regarding medical treatment in cases of terminal health or persistent vegetative state. This law addresses the right of privacy and recognizes the autonomy of the individual, in line with the country's constitution, which attests to the inviolable character of human dignity.

In 2001, Law 160⁵⁷ was approved to grant those over the age of 21, in full possession of their mental faculties, the right to choose the kind of treatment they want or not if they ever find themselves terminally ill or in a persistent vegetative state. It also makes it possible to appoint an assignee. The Advance Healthcare Directives must be registered in a notary's office and may be declared in the presence of a doctor and two witnesses who cannot be heirs. The law binds the doctor and the health institution to the execution of the document. Peculiarly, this law states that if the patient is pregnant, the directive will only be enforced once the baby is born.

Argentina

In Argentina, the directives were first established in each province, and later, at the federal level. In 2004, the Board of Trustees of the province of Buenos Aires approved the Register of Self-Protection Act and Prevention of Potential Disability⁹ as a way to legalize the living will in the province. In 2007, Rio Negro became the first province to establish the right to AHD, based on Law 4.263 – *Advance Will Law*⁵⁸. In 2008, the province of Neuquén, with Law 2.611⁵⁹; and in October 2009, Federal Law 26.529⁶⁰ was promulgated.

Questions regarding patient autonomy made it difficult to accept the document, which required the parliament to further discuss the issue in order to elaborate another law ensuring this right²⁸. Pressed by the population that debated the Selva Hebrón and Melina Gonzalez cases, legislators enacted Law 26.742 in 2012⁶¹, modifying some of the articles established in the previous legislation.

According to this law, the directives can be elaborated by an adult person who is capable of consenting or refusing preventive or palliative medical treatment. Unless the practices implied do not lead to euthanasia, the assistant doctor is obliged to accept the directives established. The Advance Healthcare Directives must be formalized in writing before two witnesses, registered by a public notary or first instance court, and revoked by the patient at any time. This law also safeguards the medical professional, clearly warning that no one who has acted upon the directives will be held civilly, criminally or administratively.

The legal text has been criticized by some authors for not including children with demonstrated coherent discernment capacity, not creating a national registration, and not determining the document format. Still, the criticism stated that the law *creates other issues, as it grants the patient the right to refuse palliative treatment, which goes against the essence of the AHD*⁶². The mandatory notary or first instance court registration were also questioned because it removes the directives from the scope of health care, risking denaturalizing them as medical act imposing requirements that will most likely hinder their bureaucratization²⁸. Despite the criticisms and problems raised regarding the execution of the document, it is important to note that a federal law exists, which regulates the existence and use of Advance Healthcare Directives in Argentina.

Mexico

The *Advance Directive Law*⁶³ was promulgated in 2008. It establishes that the document can be elaborated by any individual who is terminally ill but capable of making his/her decisions; or by relatives, if the patient is unequivocally unable to do so. It must be drafted and signed at a notary's office. If the patient is unable to go to the notary's office, the document can be composed in the presence of health professionals and two witnesses, being sent for registration afterwards.

Persons related up to the fourth degree of affinity or consanguinity cannot be witnesses, neither those who are younger than sixteen years old or do not understand the patient's language, which of whom can be convicted of false testimony. An unpaid voluntary representative, but compulsory after acceptance, will be appointed. His/her duty is to ensure that the provisions are met exactly how they have been drafted and not act as a substitute decision-maker.

The document can be revoked at any time by the patient, and in cases of duplicity, the most recent will be the one legally valid. The record may also contain information on organ and tissue transplant. The patient must inform the health team about the existence of the directives, which must be obeyed according to the decisions made.

If the content of the document is incompatible with the ethical, moral and religious principles of the health professional, the latter reserves the right to declare an objection of conscience to exempt him/herself from the request. The Department of Health will be responsible for ensuring and supervising health institutions so that qualified, compliant personnel are available so that the policies are met. Euthanasia is

expressly prohibited, and at no time or under any circumstance may health professionals administer medications or treatments that intentionally cause the death of a terminally-ill patient.

Based on a sample of 278 people to evaluate the knowledge of the Mexican population on AHD, Cantú and Alberú²⁹ state that 64% of them are unaware of the law. The authors were surprised and bemoaned the low dissemination of Advance Healthcare Directives by authorities, arguing that other laws were widely publicized through TV, the Internet and in public transport, even though they had bioethical implications. Despite the comment, the authors do not delve into the reasons related to the lack of publicity.

Uruguay

Law 18.473⁶⁴, of April 2009, authorized the Advance Healthcare Directives across Uruguayan territory; being regulated by Decree 385/2013⁶⁵. According to the legal text, patients can express in advance their willingness to oppose the future application of medical treatment and procedures that extend their existence. This manifestation is restricted to cases of incurable, irreversible and terminal disease.

The document may be written by persons over the age of 18 who are psychically competent; and the refusal to medical treatment or procedure is only valid if it does not affect the lives of others. A representative must also be indicated in the document, which must be signed to be recognized legally; have been witnessed by two persons who have no connection with the doctor in charge and have been drawn up according to the form regulated by the decree. In addition, the document must be registered at a notary's office and included in the patient's medical history. The statement may be revoked at any time by the patient, either verbally or in writing.

It is important to note that the doctor in charge must communicate all cases of suspension of treatment covered by this law to the bioethics committee of the institution, if any. These cases must be analyzed within 48 hours after receipt, which can be interpreted as non-compliance with the directives. If the committee does not come to a decision, the suspension shall be considered tacitly approved.

According to the Uruguayan legislation, the patient can also use AHD to request treatment¹², which means that patients can consent in advance⁶⁶. In Uruguay, the patient's manifestation regarding the aspects of his/her life and health care has been possible for a long time. Before that, Law 14.005/1971⁶⁷ regulated advance directives on organ donation, and

there was still, based on the code in force in 1934, the criminal figure of pious homicide, type of euthanasia⁶⁶.

Colombia

In Colombia, the topic AHD was addressed in the code that regulates access to palliative care. Law 1.733/2014, known as *Consuelo Devis Saavedra Law*⁶⁸, states that terminally ill patients, suffering from degenerative and irreversible chronic disease, have the right to information about their illness and treatment, second professional opinion, in addition to palliative care, to actively participate in decisions and prepare advance directives.

It states that in order to register AHD it is necessary to be of age, making full use of legal and mental capacities, healthy or sick, and able to understand the implications of the document. However, there is no reference as to how to register, which directives are accepted or their validity. In addition to patients' rights, it informs the doctor duties and the obligations of public and private health institutions. It also informs if the patient is an organ donor or not.

Brazil

The discussions on the subject appear to be still embryonic in Brazil. Because it is ignored by politicians, it leaves a void in the legislation, causing health professionals to feel insecure when dealing with the topic⁶⁹. AHD have never been specifically regulated in the legal framework. Despite the lack of attention paid to the subject, there are several references to the right to refuse treatment in the Brazilian legislation.

The Federal Constitution of 1988 presents in Article 1, item III, the concept of dignity of the human individual as one of the foundations of the Republic⁷⁰; and article 5, item II, establishes that *nobody will be obliged to do or not to do anything but in the name of the law*⁷¹. In the same spirit of ensuring dignity and freedom, Law 10.741/2003, article 17, known as the Statute of the Elderly, states that *the elderly who are in the domain of their mental capacity are guaranteed the right to choose the health treatment deemed more favorable*⁷².

The Civil Code also states, in article 15, that *no one may be compelled to undergo life-threatening medical treatment or surgical intervention*⁷³. This device *clearly expresses the autonomy of the patient in relation to the treatments to be administered*⁷⁴. The interpretation of these concepts represent the basis for the validity of Advance Healthcare Directives within the Brazilian legal system.

In São Paulo, Law 10.241/1999 (Mário Covas Law), section XXIII, article 2, ensures the users of

the state health service the right to *refuse painful or extraordinary treatment intended to extend life*⁷⁵. The guarantee of this right echoes in Paraná in section XXIX, article 2 of Law 14.254/2003⁷⁶; and in Minas Gerais, article 2, section XXI of Law 16.279/2006⁷⁷. Although the legislation ensures the early disposition of treatment, none of the articles guarantees any right to the patient if he/she is unconscious or unable to express his/her will. Likewise, they do not advise on any documentation that supports this right.

Advance Healthcare Directives gained visibility in the Brazil after the promulgation of Resolution CFM 1.995/2012⁷⁸, which deals with the subject in order to adapt the medical conduct. Article 2 of the same resolution states that *as far as decisions about care and treatment of patients who are unable to communicate, or to freely and independently express their wishes, the physician will take into account their advance healthcare directives*⁷⁸.

This resolution represents a historical landmark, even if it fails to address all facets of the issue. However, it is necessary to point out that this device did not legalize the AHD in the country because *it is deprived of force of law, since the Federal Council of Medicine does not have the power to legislate*⁷⁹. Nevertheless, since this is the first regulation, it can trigger the legalization of the directives, if a legal order follows the *natural tendency to adopt previously positions in the ethical scope so that the Legislative Power finally consolidates them within the legal scope*⁸⁰. The Senate Bill 524/2009⁸¹ addressed the issue, providing for the right of the terminal patient. However, this project was terminated on April 14, 2015 without ever being voted for.

Resolution CFM 1.995/2012⁷⁸ represented an important advance, even though it has not been passed yet and it is restricted to a certain professional class. Some aspects observed in the Resolution resemble the ones included in the legislation of other countries as far as the preparation of the document, such as the possibility of appointing a representative; the determination that the directives prevail over any non-medical opinion, including the wishes of family members; and the prohibition of Advance Healthcare Directives that do not comply with the code of medical ethics. However, important aspects are missing, such as the appointment of the designated representative, the minimum age required for the registration of the document, the types of treatment that can be refused, or if there is validity period.

The Resolution⁷⁸ recommends the inclusion of the AHD in the patient's medical record, but does not mention the need for witnesses, which may cast doubt on the veracity and validity of what is written

down. Although it is not in the scope of the resolution, Dadalto *claims the indispensability of the preparation of Advance Healthcare Directives by public deed before a notary, in order to guarantee their lawful purpose in view of the fact that there is no specific legislation in the country on the subject*⁸². Thus, legal advice is highly recommended, including the registration at a notary's office of any documents regarding the patient's wishes as far as health care is concerned.

In 2013, the Public Ministry of Goiás filed a public civil action challenging the constitutionality of the resolution, deemed constitutional on April 2, 2014⁸³. The sentence validates the instrument for any patient who is unable to express their will and points out the need for a stronger legislation on the subject. It also grants the family and the public authority the right to seek the Judiciary if they are contrary to the Advance Healthcare Directives provisions or wish to make a claim against health professionals for illicit behavior⁸³.

AHD, or, as it is being known in Brazil — the living will, has been featured punctually in newspapers and magazines, bringing the matter closer to the public's eye. In 2012, an electronic portal was launched where it is possible to access information about the theme⁸⁴. A private database is available for the registration of directives. In the launching year, the site received 10,000 accesses. That number increased to 100,000 in the following year, remaining the same during 2014 and 2015⁸⁴. Regarding the registration of Advance Healthcare Directives at a notary's office, the number increased by 771% between 2012 and 2016⁸⁵. This significant increase seems to point out the interest of people in the subject and how much they wish to register their will.

Regarding the knowledge of professionals and students on the subject, a study carried out in the state of Pará in September 2013 including 238 medical students, ranging from the 1st to the 8th semester, found that only 8% of those surveyed demonstrated a clear understanding of the meaning of the term "living will"⁸⁶. Another survey carried out with 351 health professionals in the city of Juiz de Fora (MG) shows that only 37.89% of the participants say they are familiar with the concept⁸⁷.

A research conducted in the western region of the state of Santa Catarina including medical and law students and professionals concluded that only 29.2% of the interviewees demonstrated full knowledge about the subject⁸⁸. Another study, conducted between June and September 2011 in a Santa Catarina university hospital in Brazil, including a sample of patients and companions, found that

94.5% of the patients and 88.7% of the companions were totally unaware of the terms⁸⁹.

In December 2017, another research was conducted including 716 people in São Paulo, 70% of these were health professionals⁹⁰. The research demonstrated that 49,6% of respondents did not know the difference between advance healthcare directives and living will; but 96.4% agreed with the prevalence of wishes expressed in the will of family members, which indicates some knowledge on the concept behind the living will.

The study also showed that 85.4% believe that the living will must be valid for all situations, whether cases of incurable and terminal degenerative diseases, or cases of persistent vegetative state. Regarding the refusal of treatment, 57.4% are in favor, including, among others, intensive care unit admission, artificial nutrition, hydration, antibiotics and cardiopulmonary resuscitation. When the subject refers to the appointment of a health care assignee, 92% agree that family members should be selected; 48.2% think that any relative can be chosen as an assignee⁹⁰. Apparently, the interviewees did not consider possible conflicts of interest between their will and that of their relatives. Based on the data presented through research, it is noticed that the advance healthcare directives still remain a very unknown subject, despite the increasing public attention.

In all the countries studied, the directives are an instrument elaborated by an adult person, enjoying full mental capacities. They must be registered at a notary's office in Uruguay, Mexico and Argentina. In Puerto Rico, Mexico, and Uruguay, the legislation blends both types of directives, including the appointment of an assignee. In Puerto Rico and Mexico, the document becomes invalid if it affects the lives of others. Except for Uruguay, which demands the validation of the directive by

a bioethics commission, all countries analyzed link doctors to institutions. In the case of Brazil, in order to ensure the legality to all those involved, it seems fundamental — as it is in other countries, that a federal law be passed to determine the preparation of the document in a non-bureaucratic way, making it easier for all users to access any information regarding the directives, including their preparation and registration.

Final considerations

Despite the growing interest and the legislation in force, adhering to Advance Healthcare Directives seems to be still difficult, which suggests the need for greater disclosure of information to the public and health professionals. However, this may not be the only obstacle for the implementation of Advance Healthcare Directives. Further investigation is still required.

It is interesting to note that the directives have been much discussed within the legal and biolaw fields, which, however, has not been replicated among health professionals. It is plausible that this occurs due to the lack of knowledge about the possibilities available through this instrument, not only with respect to the exercise of patient autonomy, but also to the protection of professionals against possible difficulties involving their relationship with the relatives of a terminally-ill patient.

It is reasonable to think that perhaps the difficulty of approaching Advance Healthcare Directives is directly linked to the difficulty of discussing and dealing with terminally-ill patient. Thus, discussing the possibility of elaborating this document could be a way to facilitate the dialogue, while exposing and clarifying anxieties, uncertainties and fears, enhancing the relationship among those involved and their quality of life.

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Renata da Silva Fontes Monteiro has prepared the study and written the article. Aluísio Gomes da Silva Junior provided guidance, contributing to the final revision.

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