

# Advance directives: the quest for the patient's autonomy

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## Abstract

This article analyzes how the autonomy and dignity of individuals in cases of terminality can be preserved using the advance directives of will. It is understood that a procedure, yet to be found or implemented in Brazil, should be sought to ensure that individuals, even when incapable of communicating, can be assured that their will by health professionals. As a method, this study seeks to deepen concepts used by doctrine, resolutions and laws. It is concluded more publicity should be assigned to the advance directives of will, informing the population about their existence and allowing people to express their desires regarding health. Furthermore, it is necessary to create a database that allows sharing an individual's expression of will with the hospital network.

**Keywords:** Advance directives. Living wills. Personal autonomy.

## Resumo

### Diretivas antecipadas de vontade: busca pela autonomia do paciente

O presente trabalho analisa como a autonomia e a dignidade do indivíduo em casos de terminalidade pode ser preservada por meio das diretivas antecipadas de vontade. Entende-se que se deve buscar uma forma, ainda não encontrada e implantada no Brasil, de fazer que o indivíduo, mesmo incapaz de se comunicar, fique seguro do conhecimento de sua vontade por parte dos profissionais de saúde. Como método, o estudo busca aprofundar conceitos utilizados pela doutrina, resoluções e leis. Conclui-se que é preciso dar mais publicidade às diretivas antecipadas de vontade, informando a população sobre sua existência e permitindo que as pessoas expressem seus desejos relativos à saúde. Ademais, é necessário criar um banco de dados que permita o compartilhamento da manifestação de vontade do indivíduo com a rede hospitalar.

**Palavras-chave:** Diretivas antecipadas. Testamentos quanto à vida. Autonomia pessoal.

## Resumen

### Directivas anticipadas de voluntad: búsqueda de la autonomía del paciente

El presente trabajo analiza cómo la autonomía y dignidad del individuo en casos de terminalidad puede ser preservada a través de las directivas anticipadas de la voluntad. Se entiende que se debe buscar un camino, aún no encontrado e implantado en Brasil, para que el individuo, incluso incapaz de comunicarse, esté seguro del conocimiento de su voluntad por parte de los profesionales de la salud. Como método, el estudio busca profundizar conceptos utilizados por doctrina, resoluciones y leyes. Se concluye que es necesario dar más publicidad a las directivas anticipadas de voluntad, informando a la población sobre su existencia y permitiendo que las personas expresen sus deseos con respecto a la salud. Además, es necesario crear una base de datos que permita compartir la manifestación de la voluntad del individuo con la red hospitalaria.

**Palabras clave:** Directivas anticipadas. Voluntad en vida. Autonomía personal.

The authors declare no conflict of interest.

Given the lack of regulation for advance directives of will (ADW) in Brazil from the point of view of ethical conduct of the physician and patient autonomy, Resolution 1,995 of the Federal Council of Medicine (CFM)<sup>1</sup> was edited in 2012. The norm also considers the existence of new technological resources whose adoption leads to *disproportionate measures that prolong the suffering of the terminally ill patient, without benefits to health, and that these measures may have been previously rejected by the patient*<sup>1</sup>.

ADW are used when the patient is unable to express their will. They establish a *set of wishes, previously and expressly expressed by the patient, about the care and treatments they wish, or not, to receive*<sup>1</sup>. If guidelines have been developed prior to admission to the hospital, the patient's representative must report the existence of the document immediately. If they are lucid and capable when entering the hospital, the patients themselves can communicate their wish to the medical team.

According to CFM's Resolution 1,995/2012<sup>1</sup>, the patient's will must prevail over any other, including of any family member. In this case, the rules of civil capacity for expression of will and the patient's legal freedom are considered. As Stephan Kirste defines, having legal freedom means *having subjective rights. The capacity for freedom is, therefore, the capacity to be the bearer of subjective rights. The holder of these rights is, then, the subject of Law or the person of Law. The protection of human dignity means, therefore, the right to recognition as a person of the Law*<sup>2</sup>.

The introduction of ADW in our society legitimizes an individual's will<sup>3</sup>, respecting their autonomy, freedom and dignity. An effective way to protect these rights must be effectively sought, allowing individuals who chose to prepare a ADW to have their decisions respected.

This article seeks to reflect on the ADW and how to implement them with respect to the patient's autonomy and right to die with dignity, treating death as the natural and expected event that it is. To this end, this study addresses the Brazilian legal system, the processing of Senate Bill 149/2018<sup>4</sup>, specific laws and implicit and explicit principles in the Brazilian Constitution.

## Human dignity as an absolute value

The idea of dignity did not appear in the 20th century, but it was then that its meaning as we know it was developed. The concept has since alluded to a value inherent to all individuals, as established by the *Universal Declaration of Human Rights* (UDHR), whose first article reads: *All human beings are born free and equal in dignity and rights*<sup>5</sup>. In this sense, Pelegrini<sup>6</sup> points out that this principle concerns the protection of the human person, enabling an existence that annihilates attacks on dignity. It is, therefore, a historic achievement for humankind.

For Sarlet, human dignity is *the intrinsic and distinctive quality of every human being that makes them worthy of the same respect and consideration by the State and the community, implying, in this sense, a complex of fundamental rights and duties that ensure the person both against any degrading and inhumane act, as they will guarantee the minimum existential conditions for a healthy life, in addition to providing and promoting their active and co-responsible participation in the destinies of their own existence and life in communion with other human beings*<sup>7</sup>.

From a theological anthropology standpoint, the community dimension of human beings as the *imago Dei* needs to be known in its entirety, recognizing its vulnerability and complexity from the concrete reality<sup>8,9</sup>. In the Judeo-Christian tradition, the dignity attributed to human beings comprises a dimension of sacredness and inviolability. In this perspective, human beings deserves all respect since whoever touches them also touches God.

The classical interpretation of Genesis does not say that the "person" is the image and likeness of God, but that God *made* them in his image and likeness. The action belongs to God, who constitutes the "person" as an interlocutor and, therefore, grants them the highest dignity. This does not make man a God, nor a demigod, but rather an image and similarity towards the filial relationship of care and communion: being a person in totality and being a person in relation to the other with equal dignity.

For humanist Pico della Mirandola, the human being is permanently self-constructing, and human

dignity is integrated with freedom, moving towards the potential life in which man, composed of Logos and Ratio, is acted by the Infinite and acts in the finite<sup>10</sup>. Baertschi<sup>11</sup> presents two meanings for dignity with regard to its moral dimension. The first is the personal sense, linked to self-respect and the achievement of moral goals. Here, dignity is not to be confused with self-esteem, which includes the achievement of personal goals.

The second sense is impersonal: *the dignity of a human individual consists in the fact that they are a person and not an animal or a thing*<sup>11</sup>. It is man's right, as the author treats, which makes the person hold *particular value, prohibiting them from being treated as simple means, like things, as observed by Kant*<sup>11</sup>. Consequently, respect for dignity refers to treating the individual as a rational being who cannot be instrumentalized, regardless of their status or conduct. Dignity, therefore, cannot be lost, as it is intertwined with human nature. Baertschi highlights that acting with respect for others is accepting the limits of our preferences on behalf of the other, even when we are at the moment of imposing our wills, as respect is recognized as a *sui generis* value, that is, each being, regardless of origin, holds particular value to be respected within the self<sup>11</sup>.

Rosen discusses the meaning of dignity as *commitment and the ability to bear suffering in an attempt to meet the demands of duty, and this obviously varies from person to person*<sup>12</sup>. Many conflicting moments regarding the dignity of the individual existed over the 20th century, especially World War II. This context further strengthened the meaning of the word "dignity" in modernity, already studied in the 18th century by Kant, who emphasized the use of reason as the main core: *all moral concepts have their origin entirely a priori in reason, and this holds as much for the most ordinary common-sense moral concepts as for the ones used in high-level theorizing; that moral concepts cannot be formed by abstraction from any empirical knowledge or, therefore, from anything contingent; that this purity or non-empiricalness of origin is what gives them the dignity of serving as supreme practical principles*<sup>13</sup>.

In addition to the evaluative and metaphysical dimension, human dignity is a legal principle.

The preparation of international documents after World War II consolidated the idea of preserving human rights and, together with the beginning of the welfare state, linked human dignity to national constitutions.

Regarding international documents, the UDHR<sup>5</sup>, proclaimed on December 10, 1948, and signed by Brazil on the same date, holds special relevance. There are also other conventions, such as the *Pact of San José in Costa Rica* (1969)<sup>14</sup>, which follows the same concept as the UDHR. All these documents are contained in the International Charter of Human Rights, built over time with the aim of *promoting and encouraging respect for human rights and fundamental freedoms for all, without distinction of race, sex, language or religion*<sup>15</sup>.

Also, with the objective of safeguarding human rights, there is the *Universal Declaration on Bioethics and Human Rights* (UDBHR)<sup>16</sup>, which promotes respect for dignity, guaranteeing respect for the lives of human beings. UDBHR addresses States, but also provides guidance for individuals where relevant. Its content is related to life sciences and associated technologies applied to human beings.

The 1988 Federal Constitution<sup>17</sup>, with the purpose of creating a democratic and social welfare state in Brazil, established the dignity of the human person as a fundamental principle. In Barroso's conception<sup>18</sup>, the Constitution is seen positively for having supported the transition from a State considered authoritarian to a democratic State governed by law. The author observes that, under the 1988 Constitution, *presidential elections have been held, by direct, secret and universal vote, with broad public debate, popular participation and alternation of political parties in power*<sup>19</sup>.

In another work, Barroso deals with the approximation between law and ethics in post-positivist culture, where law becomes an *instrument of legitimacy, justice and the realization of human dignity*<sup>20</sup>. The 1988 Constitution, based on this post-positivist model, provides for the guarantee of human dignity as a fundamental principle, placing it in a position of superiority in relation to other principles.

It is in this sense, and aiming at the dignity of the human person, that the choice of the

impaired individual to express themselves freely and autonomously must be preserved. For this purpose, ADW were recognized in CFM's Resolution 1,995/2012. Such directives have two objectives: to formulate and express the patient's wishes<sup>21</sup>.

Self-determination is an essential aspect of human dignity and freedom. Possible interpretation issues and conflicts between physicians and family members must be overcome to guarantee it, as to respect the choices of the subject weakened by the illness that plagues them. The problems surrounding the autonomy of the will pose several challenges to contemporary bioethics.

### Advance directives of will

Advance directives aim to protect the patient's self-determination and autonomy, indicating how they want to be treated (in terms of treatments to which they want or not to be subjected to) in situations of serious illness and unconsciousness. Such directives are listed in the Patient Self-Determination Act, an US law that recognizes the refusal of medical treatment, aiming at the patient's autonomy in disability cases.

In Brazil, there is still no law that broadly addresses advance directives, but there are constitutional principles, resolutions and state laws that provide for patient autonomy. As an example, we can cite CFM's Resolution 1,995/2012<sup>1</sup>; the constitutional principle of human dignity and autonomy<sup>17</sup>; entrenched clauses, such as the one that prohibits inhuman treatment; and state laws that emphasize the refusal of painful treatments or extraordinary benefits for prolonging life: Law 10,241/1999<sup>22</sup> of the State of São Paulo (Law Mário Covas), Law 16,279/2006<sup>23</sup> of the State of Minas Gerais and Law 14,254/2003<sup>24</sup> of the State of Paraná. Also, article 15 of the 2002 Civil Code, which provides that *no one can be constrained to undergo, at risk of life, medical treatment or surgical intervention*<sup>25</sup>.

Kovács<sup>26</sup>, in his article "Autonomy and the right of dying with dignity," presents a panorama of changes between the Middle Ages and the

20th century with regard to death. According to the author, in the Middle Ages death was seen as something expected, familiar and tamed. The moments that preceded it were dedicated to signing the will and ensuring that the person's wishes were respected after death. In the 20th century, the path to death becomes a slow process, with lengthy treatments and often associated with pain and suffering.

Although every historical period deals with death differently, it is up to each subject to live it in the way that suits them best. However, death remains a taboo and faced only when extremely necessary, such as in cases of poor prognosis or serious diseases, in which there is little chance of life for the patient<sup>26</sup>.

Brazil needs a regulatory norm that validates advance directives to guarantee not only a life with dignity, but also a death with it, always taking into account the patient's autonomy. As Godinho points out, *if life, on the one hand, is not an available legal asset, on the other, a duty to live at all costs should not be imposed on people, which means, thus, that dying with dignity is nothing but a logical consequence of the principle of human dignity. Given the above, it remains to be concluded that the living will not only must find space in the Brazilian legal system, but its validity must also be recognized by law, which enshrines the person's right to self-determination regarding the means of medical treatment that they intend or not to be submitted to*<sup>27</sup>.

Having a dignified death is nothing more than dying without impositions from others. Life is an unavailable legal asset, which corresponds to the rights linked to personality. Thus, the legislation must guarantee the right to die with dignity, caring for the patient's life and physical integrity.

### Advance directives of will in Brazil

As already mentioned, there is no regulatory norm for ADW in Brazil, but the interpretation of infraconstitutional norms must be considered, such as article 1 of the Mário Covas Law<sup>22</sup> and implicit and explicit principles in the Constitution. These norms are added to the CFM Resolution 1995/2012<sup>1</sup>, which aims to defend the validity of ADW in the country.

Considering the inexistence of specific legislation, to guarantee legal certainty, Dadalto<sup>28</sup> defends drafting directives by public deeds made by a notary. The author lists a series of definitions about this instrument:

d) ADW cannot contain patrimonial provisions, as they are documents expressing the will to refuse and accept health care, also containing the appointment of a third party to decide on behalf of the grantor when they are unable to express, in an autonomous way, their will; e) ADW cannot be included in public deeds of a public will, constitution of a stable union or any other document, as they refer to sui generis legal relationships, which involve ethical issues of the physician-patient relationship. Furthermore, they have their own requirements and specificities, which cannot be confused with those of other institutes; f) ADW, in Brazil, cannot have provisions on organ donation, since law 9,434/97, amended by law 10,211/01, establishes that the will of the deceased's family member prevails over the will of the deceased, manifested in life and, therefore, it is contrary to ADW, in which the will expressed by the grantor prevails over the will of family members and health professionals; g) The requirement for witnesses to register the ADW is arbitrary, since there is no law regulating the solemnities of this document in Brazil; however, it is essential that the representative signs the ADW, accepting the position for which they are being appointed; h) grantors who have already been diagnosed with an incurable and terminal disease must prove their judgment through a medical report, since medical studies question the effects that an end-of-life diagnosis has on the individual's judgment; i) it is important to guide the grantor to seek a physician in order to obtain technical information about the care to which they wish to express acceptance or refusal; j) if the grantor is guided by the physician and the physician agrees, it is possible to write down the physician's name and CRM number, so that they can be contacted if questions about the information provided by the patient are raised<sup>29</sup>.

The patient must be aware of what ADW are and what cannot be included in them. In Dadalto's<sup>28</sup> statements, the exact science of

the disease and consultation with a professional in the medical field are especially important, since they will clear any doubts regarding procedures and treatments, helping the patient to make informed decisions.

According to Dadalto<sup>28</sup>, considering that the registration of documents referring to directives in notary offices across the country should be standardized, a national registry similar to the Spanish and Portuguese ones should be created to effectively fulfill the individual's will. Aiming to inform professionals who will enforce the directives and therefore need to know their existence, we propose to go beyond this national registry with the creation of a computerized network that allows hospitals to quickly know the patient's previous manifestations. According to Dadalto<sup>28</sup>, ADW must be published as soon as possible in the National Registry by the notary's office. This record is a step towards publicizing the patient's will, aiming to guarantee their autonomy.

Thus, it is worth emphasizing a research project carried out in notaries in Porto Alegre, Rio Grande do Sul<sup>30</sup>, which measured the knowledge of the population and notaries about ADW. Twelve people responsible for their respective notary offices were interviewed, and the results showed that 66.7% say they know ADW, but the records of this document are less than three per notary office. According to the authors, *although AD emerged from the desire of society, there is still little demand in notary offices. It was emphasized that, although this registration is not mandatory, nor is there a law that imposes this need on notaries, there is legal certainty attributed to the acts signed before a notary, which should represent a greater demand from interested parties, in the competent bodies*<sup>31</sup>.

Although they lacked knowledge of CFM's Resolution 1,995/2012<sup>1</sup>, notaries were open and favorable to the public registration of the modality. In practice, such registration is the way to guarantee the existence and validity of the document. The study also highlights the importance of standardizing the requirements and form of document registration, which highlights the role of the legislative sphere in the creation of a specific law for ADW, providing legal certainty and effectiveness to the instrument.

In Brazil, Senate Bill 149/2018<sup>4</sup> is being discussed, which provides for ADW for incapacity cases (terminal stage or serious or incurable illness), in times of subordination or insubordination to treatments considered futile or extraordinary. The bill underlines, in its 2nd article, the definition of ADW as a manifestation of the patient's will made by public deed, without financial content, on whether or not to receive certain care or treatments if they are not in a position to express their will freely and autonomously.

The bill states that every adult and capable person will be able to declare their willingness to receive or not medical treatment in case of disability, and that such willingness must be recognized by a public deed *without financial content, drawn up in a competent registry*<sup>4</sup>. Also, according to the bill, the directives may be revoked in whole or in part at any time, by the patient or by verbal declaration to the patient's healthcare provider. In the second case, the registration must be done by the attending physician.

As justification, the bill considers the advancement of medical technology with the objective of prolonging life and the consequent topicality of the topic, which made several countries legislate on ADW. The project, therefore, aims to fill the legal gap regarding the subject. In the project author's words, senator Lasier Martin, *in recent decades, we have witnessed great technological development in the medical field, which has contributed to prolonging life through intensive clinical support. On the one hand, it is undeniable that the advances observed have brought benefits to countless people with serious illnesses. On the other hand, several questions have arisen in the field of bioethics, especially regarding themes such as the end of life and the autonomy of people in deciding on the treatments they wish to undergo, especially those with advanced-stage disease and no prospect of cure*<sup>4</sup>.

ADWs are an advance in terms of individual rights, life with dignity and individual autonomy. It is, therefore, necessary to regulate its registration, with a single model, ensuring the legal security of the document. However, as long as this legislative gap exists, it is up to the lawyer to instruct the grantor to prepare the document without illegal acts, in a judicious and well-founded manner, since fragile documents can later be annulled by the Judiciary.

## National communication network

Given the current scenario of ADW in Brazil, the probability of failure in preserving an individual's will is high, since there is no way for a patient to communicate their will to the health system. CFM's Resolution 1,995/2012<sup>1</sup> provides for the possibility of appointing a representative to communicate the patient's wishes. However, how to know if this person knows the exact moment when it is necessary to inform about the previously elaborated policy? If the ADW registration is not publicized, such registration, which seems to be the most adequate, becomes flawed. And "publicizing," here, does not only refer to access to the document in the registry, but above all to the availability of directives for those who must comply with them: health professionals.

Thus, how to ensure that the autonomy of an individual's will be safeguarded? Would not Brazilian legislation be failing in the task of ensuring autonomy defined according to contemporary ethical theory<sup>32</sup>, such as the ability to ponder and identify desires or preferences, considering intentionality and understanding?

What is proposed, in times of so much technology and connection, is the creation of a system that links notary offices and the health system. This system would help to preserve autonomy and ensure respect for the dignity of the individual who chose to draft advance directives. When the individual enters the hospital, if the professionals have this information, it will be easier to effectively comply with the patient's wishes.

A model for ADW can be the death certificate, a *base document of the Mortality Information System of the Ministry of Health (SIM/MS)*<sup>33</sup>, issued by the physician based on an official form. This declaration enables research work and knowledge of the country's situation with regard to mortality statistics. It is worth emphasizing that the physician who issues the death certificate is ethically and legally responsible for filling up and signing the document, as well as for the information recorded, pursuant to article 1 of CFM's Resolution 1,779/2005<sup>34</sup>.

In the case of ADW, the responsibility for entering the declaration data could or could not be the responsibility of health professionals. If the patient

has already registered their policies in a registry office, the information is already available. However, if the patient expresses their wishes when entering the hospital, the registration in the system could be the responsibility of the health professional.

Before implementing a unified system, legislative regulation is needed to standardize the ADW in notarial terms. As for public knowledge, such a system would be enough for the information to reach the knowledge of health professionals. With this, complying with an individual's provisions would be easier and safer.

### Final considerations

The recognition of the dignity of the human person, included in the Brazilian legal system,

was a significant achievement. It should be noted, however, the insufficiency of the country's legislation with regard to ADW, which deal with the choice of being submitted or not to a treatment considered futile, aiming to preserve the patient's autonomy.

The criticism exposed here regarding the gaps on the subject considers the possibility of approval of Senate Bill 149/2018<sup>4</sup>, which seeks to bring legal certainty to the declaration of ADW. In addition to this project, currently in progress, the creation of an interconnected communication system is also proposed, which would allow the sharing of the ADW of an individual with whom they must carry them out (the health system). It is urgent to create the proposed computerized system so the directives can be consulted and the individual's autonomy achieved.


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All authors participated in the idealization, elaboration and review of the work.

**Received:** 4.15.2020

**Revised:** 7.15.2021

**Approved:** 8.6.2021