

# Advance directives: patient autonomy and professional safety

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## Abstract

This theoretical study discusses bioethics in the sense of safely promoting and ensuring the patients' dignity, respectful of their decision making, following regulations and protocols that help fulfill this will and bring safety to the care team. The lack of clear and consensual legal regulations on how to elaborate an advance directive generates uncertainty among healthcare providers, patients and their families. Beyond legal standardization, professionals must also have full knowledge on the topic to correctly guide and inform their patients, thus guaranteeing this right. But ensuring the right to express one's will is not enough—one must be assured that such wishes will be fulfilled. Further and broader discussions on this topic anchored on the Brazilian reality are needed.

**Keywords:** Living wills. Advance directives. Right to die.

## Resumo

### Diretivas antecipadas da vontade: autonomia do paciente e segurança profissional

Este estudo teórico discorre sobre a bioética no sentido de promover e assegurar a dignidade do paciente de uma forma segura, que obedeça a sua tomada de decisão, seguindo normativas e protocolos que garantam o cumprimento dessa vontade, e trazendo também segurança para equipe assistencial. A ausência de consenso no meio jurídico, por falta de regulamentações que explicitem as regras para a elaboração de um modelo de diretivas de vontade, gera insegurança nos profissionais de saúde envolvidos, familiares e paciente. Para garantir esse direito, além da normatização jurídica, é necessário que os profissionais tenham pleno conhecimento do assunto, a fim de orientar e informar corretamente seus pacientes. Não basta assegurar ao indivíduo o direito de manifestar sua vontade, é preciso ainda a certeza de que esta será cumprida. Há a necessidade de ampliar discussões acerca da temática, com ênfase na realidade brasileira.

**Palavras-chave:** Testamentos quanto à vida. Diretivas antecipadas. Direito a morrer.

## Resumen

### Directivas anticipadas de voluntad: autonomía del paciente y seguridad profesional

Este estudio teórico trata la bioética en el sentido de promover y garantizar la dignidad del paciente de forma segura, que acepte su toma de decisiones, siguiendo normas y protocolos que garanticen el cumplimiento de esa voluntad, además de brindar seguridad al equipo de atención. La falta de consenso en el ámbito legal respecto a normativa para la elaboración de un modelo de directivas de voluntad produce inseguridad en los profesionales de la salud involucrados, familiares y pacientes. La garantía de este derecho, además de la regulación legal, requiere que los profesionales conozcan el tema para orientar e informar correctamente a sus pacientes. No basta con garantizar al individuo el derecho a expresar su voluntad, sino que también es necesario la certeza de que esta se cumplirá. Son necesarios más estudios para ampliar las discusiones sobre el tema, con énfasis en el contexto brasileño.

**Palabras clave:** Voluntad en vida. Directivas anticipadas. Derecho a morir.

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In recent times, advances related to the well-being of terminal patients have prolonged the life duration of many people<sup>1</sup>. Thus, the dignity and autonomy of individuals in the terminal stage become elements that direct decision-making<sup>2</sup> at the end of life, a complex period for both individuals in the dying process and others involved<sup>3</sup>.

At the end of life, as at any other time, human dignity deserves to be respected and the patient must be involved in the decision-making process, to exercise their autonomy<sup>4</sup>, which represents the freedom of choice in choosing which treatments they want or not to receive<sup>5</sup>. As a result of these aspects, there are the advance directives, which are the object of the patient's manifestation of will for medical treatment<sup>6</sup>.

Given the great divergence between concepts and the absence of greater legal certainty that supports physician and patient in decision-making regarding end of life, it is necessary to discuss palliative care, living will, orthothanasia and advance directives. Therefore, using protocols and other documents that respect these wishes and bring security and legal support to the care team is essential.

Thus, this study aims to propose a review about bioethics, in order to promote and ensure the dignity of the patient safely, with respect to their decision-making and obeying the regulations and protocols that promote safety in the fulfillment of this will, in addition to bringing safety to the care team.

## Method

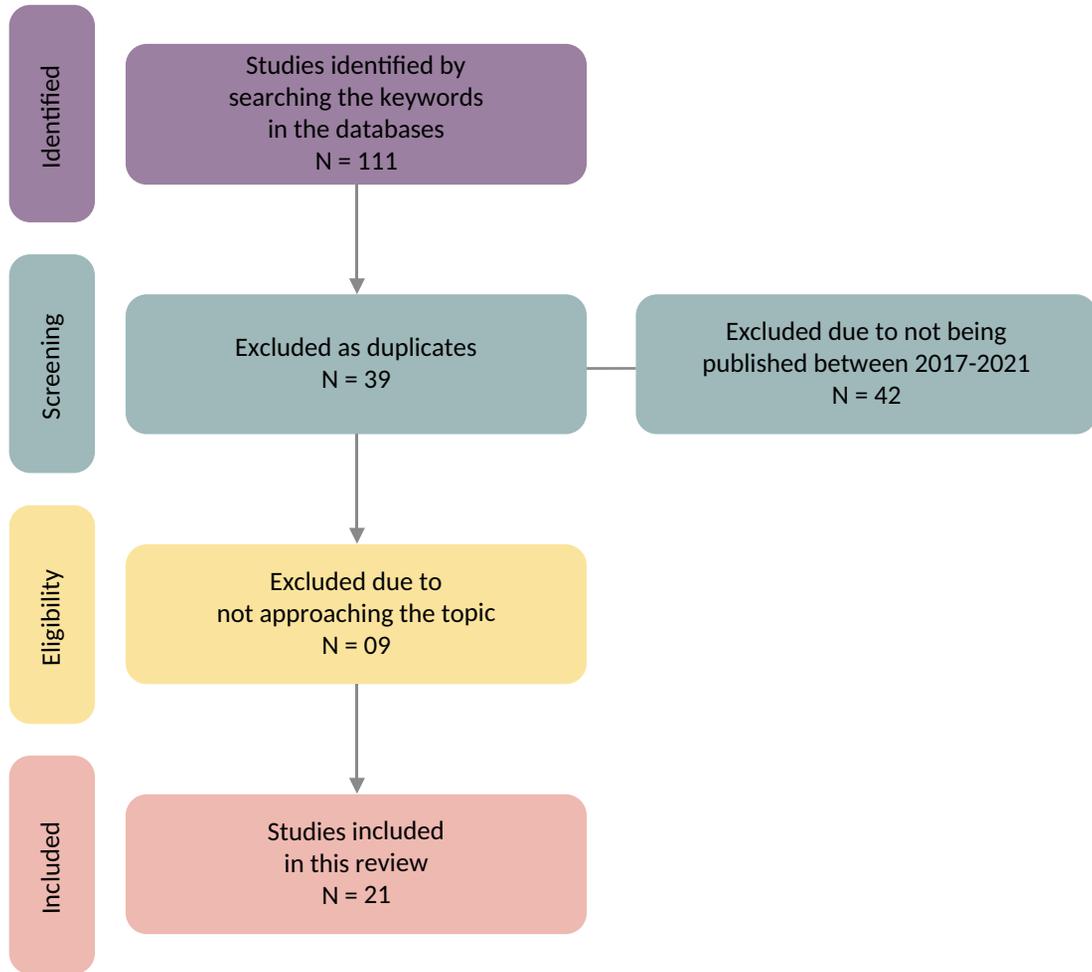
This bibliographic review searched articles published in Brazil in the SciELO, LILACS and MEDLINE databases to collect data related to the Brazilian reality. The following terms were used: "living will," "advance directives" and "orthothanasia." Studies that met the following inclusion criteria were selected: original Brazilian articles and/or literature reviews published in the period from 2017 to 2021, excluding studies that were outside the proposed theme (Table 1).

**Table 1.** Number of references found in the databases used, according to the defined search terms

Database	Number of references by search terms		
	Living will	Advance directives	Orthothanasia
SciELO	11	18	20
LILACS	18	22	18
MEDLINE	0	4	0

With these terms, a total of 111 references were found. Beginning the analysis, it was observed that, despite containing the keywords, many of these references were inconsistent with the proposed theme or were duplicated (Figure 1).

**Figure 1.** Literature review flowchart



## Results and discussion

This study was developed with data from 21 references, two review articles, one update article and 18 original articles (Chart 1).

In order to better present this subject, advance directives, central focus of the set of sources studied, some issues need to be discussed, such as patient autonomy, orthothanasia, palliative care, principles of bioethics and legal protection.

**Chart 1.** Overview of the main information of the studies surveyed in the review

Author/year of publication	Title	Type of reference	Main information
Cano and collaborators; 2020 <sup>7</sup>	“Finitude da vida: compreensão conceitual da eutanásia, distanásia e ortotanásia”	Original article	Application of a questionnaire on the knowledge and conduct of physicians in relation to orthothanasia
Cogo and collaborators; 2019 <sup>8</sup>	“Concepções médicas e dos cuidadores familiares diante das diretivas antecipadas de vontade”	Original article	Application of a questionnaire to physicians and caregivers of end-of-life patients

continues...

Chart 1. Continuation

Author/year of publication	Title	Type of reference	Main information
Cogo, Lunardi; 2018 <sup>9</sup>	“Diretivas antecipadas: uma análise documental no contexto mundial”	Original article	Documentary analysis on guidelines presented in the legislation of different countries on advance directives and living will
Cogo, Lunardi, Nietzsche; 2017 <sup>10</sup>	“Considerações acerca da atuação do enfermeiro na aplicabilidade das diretivas antecipadas de vontade”	Original article	Application of a questionnaire on how nurses understand the applicability of advance directives at the end of life
Cogo and collaborators; 2018 <sup>11</sup>	“Terminal patient care: advantages on the applicability of anticipated will directives in the hospital context”	Original article	Interview with nurses, physicians and families of terminally ill patients on the application of advance directives
Comin and collaborators; 2017 <sup>12</sup>	“Percepción de los pacientes oncológicos sobre la terminalidad de la vida”	Original article	Questionnaire on the perception of cancer patients in the face of terminality of life
Costa, Caldato, Furlaneto; 2020 <sup>13</sup>	“Percepção de formandos de medicina sobre a terminalidade da vida”	Original article	Questionnaire on the perception of medical students about end-of-life palliative care
Ferreira, Nascimento, Sá; 2018 <sup>14</sup>	“Profissionais de saúde: um ponto de vista sobre a morte e a distanásia”	Original article	Interview with health professionals involved with terminal patients about their perception of the dying process and their preparation for providing end-of-life care
Gomes and collaborators; 2018 <sup>15</sup>	“Advance directives in geriatric medicine”	Original article	Questionnaire evaluating the advance directive-related level of knowledge and intentions of caregivers of older adult patients, medical professors and students
Kulicz and collaborators; 2018 <sup>16</sup>	“Terminalidade e testamento vital: o conhecimento de estudantes de medicina”	Original article	Questionnaire on the perception of medical students about end-of-life palliative care
Lima; 2018 <sup>17</sup>	“Testamento vital à luz do ordenamento jurídico brasileiro e o princípio <i>pro homine</i> ”	Original article	Analysis of whether the living will represents a means to safeguard the applicability of Resolution No. 1.995/2012, of the Federal Council of Medicine
Mendes and collaborators; 2019 <sup>18</sup>	“Testamento vital: conhecimentos e atitudes de alunos internos de um curso de medicina”	Original article	Evaluation of the level of understanding of medical students about the living will and decisions involving the end of life
Monteiro, Silva Junior; 2019 <sup>19</sup>	“Advance directive: historical course in Latin America”	Original article	It sought to understand the use of advance directives and traced their historical course in Latin American countries that already have consolidated legislation
Moreira and collaborators; 2017 <sup>2</sup>	“Testamento vital en la práctica médica: la comprensión de los profesionales”	Original article	Questionnaire about the introduction of patient advance directives, or living will, in medical practice
Oneti, Oliveira Barreto, Martins; 2017 <sup>20</sup>	“Percepção dos profissionais de enfermagem frente à prática da distanásia e ortotanásia”	Review article	Review on the perception of nursing professionals and students regarding the practice of dysthanasia and orthothanasia

continues...

Chart 1. Continuation

Author/year of publication	Title	Type of reference	Main information
Pereira, Rangel, Giffoni; 2019 <sup>21</sup>	“Identificação do nível de conhecimento em cuidados paliativos na formação médica em uma escola de medicina de Goiás”	Original article	Questionnaire to assess the level of knowledge in palliative care of medical students
Pirôpo and collaborators; 2018 <sup>22</sup>	“Interface do testamento vital com a bioética, atuação profissional e autonomia do paciente”	Review article	Review on the relation between the living will and bioethical aspects
Pittelli, Oliveira, Nazareth; 2021 <sup>23</sup>	“Diretivas antecipadas de vontade: proposta de instrumento único”	Update article	Reflection on the characteristics and purposes of the patient advance directive document
Saïoron and collaborators; 2017 <sup>24</sup>	“Diretivas antecipadas de vontade: desafios legais e educacionais na visão de enfermeiros”	Original article	Interview on the use of advance directives in ethical-legal and educational terms in the view of nurses
Santana and collaborators; 2017 <sup>25</sup>	“Ortotanásia nas unidades de terapia intensiva: percepção dos enfermeiros”	Original article	Interview on the meaning of the process of dying with dignity in an intensive care unit in the perception of nurses
Scottini, Siqueira, Moritz; 2018 <sup>26</sup>	“Derecho de los pacientes a las directivas anticipadas de voluntad”	Original article	Investigation of the knowledge of patients with terminal diseases about their diagnosis, prognosis and the possibility of recording their desires at the end of life in the form of advance directives

## Patient autonomy

Patient participation in the decision-making process regarding their treatment is already a reality in Brazil. Numerous cases can be found in this regard, such as the latest edition of the Code of Medical Ethics (CEM) and the approval of the Resolution of the Federal Council of Medicine (CFM) on advance directives<sup>27</sup>.

According to Pessini and Hossne<sup>28</sup>, the CEM approved in 2009 established the need to recognize the patient's autonomy. In order to ensure the expression of the patients' will, CFM Resolution 1,955/2012, as pointed out by Dadalto<sup>29</sup>, established the advance directives, which have the following characteristics: 1) directive, as it is a guideline, and not an obligation; 2) advance because it is said beforehand; and 3) will based on the ability to make decisions aimed at their best interest.

The patient's expression of will, in advance, guarantees to them the right to decide how they wish to conduct the last moments of their life.

The loss of consciousness and of the ability to make decisions and communicate them in the final stage of life cannot take away from the individual the power to decide their life project in advance<sup>30</sup>.

## Advance directives

Advance directives can be defined as written instructions in which the person, in a free and informed way, exposes their wills and positions, in order to guide future decisions related to their health. They can be written by all adult individuals, regardless of their current state of health, and become effective from the moment there is medical evidence that the patient is unable to make decisions<sup>31,32</sup>.

There are two types of advance directives: durable healthcare power of attorney and living will. The first corresponds to the appointment, by the person, of someone trusted to make decisions about their health care, in case of becoming incapable. The living will, in turn,

is a legal document in which the patient has the autonomy to define what kind of medical procedure they wish to be submitted to when their clinical condition is irreversible and they can no longer make decisions<sup>31,32</sup>.

The discussion on advance directives pervades the question of the dignity of the human person and of dignified death. As death is a phase that belongs to life, it should not be ignored, and it is necessary to guarantee the right to dignity. Thus, physicians have a fundamental role in the face of terminality, because, by respecting the final provisions of the patient, they are also conferring dignity to this moment<sup>33</sup>.

This issue also involves other concepts, equally important for this discussion: euthanasia, dysthanasia, orthothanasia and assisted suicide.

### Euthanasia, dysthanasia, orthothanasia and assisted suicide

According to Mallet<sup>34</sup>, euthanasia is a practice not allowed in Brazil through which the patient's life is shortened, characterizing favoring of death. It may be active or passive, and occurs, respectively, by action of third parties or by omission of third parties. Dysthanasia, on the other hand, according to Diniz, is characterized as an *exaggerated prolongation of the death of a terminal patient undergoing useless treatment*<sup>35</sup>. Assisted suicide consists in the patient ending their own life with the help or assistance of a third party<sup>36</sup>.

As an alternative to euthanasia and dysthanasia, there is orthothanasia, a situation in which the physician adopts a posture that aims to ensure the greatest possible comfort to the patient and allows tranquility when dying. This conduct is in line with what is proposed by palliative care<sup>33</sup>.

Given the lack of regulation on the subject, CFM Resolution 1,955/2012 was created to provide security to physicians<sup>29</sup>. According to Lima<sup>17</sup>, the living will seeks the achievement of orthothanasia, which is the non-extension of life when death is imminent, with suspension of medications or artificial means that alleviate pain or prolong the life of the patient.

According to Diniz, *orthothanasia is the act of letting die in its right time, without abbreviation or disproportionate extension, by suspending a vital measure or shutting down sophisticated machines, which replace and control organs that go into dysfunction. (...) In orthothanasia, there is no deliberation to cause death, but the cessation of an act that will prolong life*<sup>35</sup>.

The concept of dignified death may imply the need for orthothanasia, which, as stated, is the non-extension by artificial means of the natural process of dying, practiced only by the physician, with the consent of the patient or family<sup>37</sup>.

Less than half of the participants in a survey conducted through a questionnaire demonstrated satisfactory knowledge of the concepts of dysthanasia, orthothanasia and euthanasia, which is worrying, since knowledge about a conduct determines its execution in practice. It is still necessary to broaden the approach to the subject in the curriculum of medical programs, including discussions on biolaw and bioethics and investing in the training of professionals who deal daily with the terminality of life<sup>7</sup>. As noted by Chehuen Neto and collaborators<sup>38</sup>, most health professionals are unaware of the living will and CFM Resolution 1,995/2012.

It is quite common to confuse passive euthanasia with orthothanasia. This association is erroneous, as shown by Dadalto<sup>31</sup>, who points out that in passive euthanasia there is an omission of common treatments and lack of palliative care, while in orthothanasia, treatments not performed are classified as extraordinary and futile.

### Palliative care

The concept of palliative care, advocated in the 1960s by the pioneers of the Saint Christopher Hospice, London, aimed above all to improve the end of life of cancer patients. This view extended to the terminal phase of other diseases and to patients of different ages, especially younger patients<sup>39</sup>.

According to Rajagopal and Palat<sup>40</sup>, the World Health Organization (WHO) proposes palliative care as an approach that aims to improve the quality of life of patients who face problems resulting from an

incurable disease and their families, by alleviating physical and spiritual suffering. Considering the importance of palliative care, it is urgent to reflect on the subject so that it is possible to bring it closer to current medical practice<sup>41</sup>.

In this discussion, it is necessary to consider the principles of bioethics proposed by Beauchamp and Childress<sup>42</sup> in 1979: beneficence, non-maleficence, autonomy and justice.

## Principles of bioethics

The four fundamental ethical principles must be applied when it comes to palliative care. If this is not the case, a significant contingent of the patients will continue, in practice, to be excluded from the system (justice), will not have their problems solved (beneficence), will continue to be treated with inappropriate methods, which often only add suffering to that induced by the disease itself (non-maleficence), and self-determination will be compromised (autonomy)<sup>43</sup>.

The living will directly aligns with these concepts, especially that of autonomy, which allows the patient to exercise their right of opinion and to have their values and desires respected, even in a moment of fragility<sup>44</sup>.

## Legal protection

The living will is an optional document that can be prepared at any time, provided that the person is 18 years of age or older or is emancipated in court<sup>17</sup>, is lucid, able and in full mental faculties. Patients can also choose to prepare a durable healthcare power of attorney, appointing someone they trust to be their attorney and make decisions about their situation, as long as there is a bond of intimacy<sup>31</sup>.

The major issue concerning the discussion on this subject is precisely the lack of consensus in the legal sphere due to the lack of regulations that establish rules for the preparation of advance directives. According to Dadalto<sup>29</sup>, CFM Resolution 1,995/2012 allows the living will to be expressed orally by the patient and recorded by the physician in their medical record, instead of in writing. According to Mallet<sup>34</sup>, the living will is valid in

Brazil and has its legitimacy guaranteed in the Federal Constitution, but specific legislation would facilitate its application and avoid controversy, which was also addressed in the study of Pittelli, Oliveira and Nazareth<sup>23</sup>.

Lingerfelt and collaborators<sup>33</sup> propose the creation of an integrated computerized system that guarantees the proper registration of patients' advance directives, which would provide a formalization of the living will and greater security to patients and health professionals.

To guarantee this right, it is necessary to formalize a Brazilian model of advance directives that is known to physicians and their teams, attached to the medical record. In addition to legal regulation, professionals have full knowledge about the subject in order to guide and inform their patients correctly.

Studies show, through questionnaires and interviews, that many professionals (physicians, nurses, students, lawyers) do not know the meaning of the living will<sup>2,7,8,10,11,13-16,18,20,21,24,25</sup>, a topic that should be known by health professionals and the population<sup>22</sup>. According to Moreira and collaborators<sup>2</sup>, physicians must be able to instruct patients on the procedures that may or may not be denied and their implications, thus ensuring that patients make conscious and informed decisions.

Saïron and collaborators<sup>24</sup> demonstrate that the lack of knowledge of the directives and the lack of legal protection, associated to the deficient approach to terminality during academic training, traditionally focused on curativism, expose a complex and challenging reality experienced by nursing professionals who work with patients in the process of dying, which leads to insecurity in these professionals and limits the work with palliative care.

In a study conducted with 100 cancer patients, 85% of them were unaware of the living will and/or the advance directives, 81% were unaware of palliative care and 70% were unaware of the do-not-resuscitate order. After being clarified about the terms used, 62% would agree to prepare a living will and/or advance directives, 82% would agree to receive home palliative care; and 64% would agree to be resuscitated in any situation, but the majority (73%) disagreed as to the practice of dysthanasia<sup>12</sup>.

Similarly, Scottini, Siqueira and Moritz<sup>26</sup> investigated the knowledge of 55 patients with terminal diseases about their diagnosis and prognosis, and the possibility of recording their desires at the end of life in the form of advance directives. Of these, only one was aware of the subject and had registered them, and three of them, after dialogue with the researcher, expressed interest in formalizing them. The others declared that they had no opportunity to talk about the topic.

In the absence of true and understandable information, the patient or family member will not be able to decide on their consent or on the therapeutic proposal. In the lack of an understanding of the information offered, the consent becomes invalid. The declaration in advance is consent for the medical act in which it is decided, at the present moment, on a situation that will be experienced in the future, and the subject of the dying process is of valuable gravity.

In this line of reasoning, Moreira and collaborators<sup>2</sup>, who evaluated the introduction of the advance directives or living will in medical practice, suggest that the physician should recommend that the patient share their decisions about the desired or refuted procedures with their family members and trusted friends.

Advance directives, as a rule, bind physicians and family members to the patient's will. Thus, it is pertinent that, during the writing of a document of this nature, a competent physician is present and there is an affinity between all those involved in the process<sup>45</sup>.

According to Cogo and Lunardi<sup>9</sup>, knowing the legislation in force in different countries corroborates the understanding that it is essential to adhere to the

advance directives, in order to prevent people who are unaware of the subject from suffering unnecessarily in the future because they have not registered their will. It is necessary to legalize the practice, in order to avoid actions that may become illegal, due to the poor protection that the Brazilian resolution provides. Although it is not law and is restricted to a certain professional class, CFM Resolution 1,995/2012, as pointed out by Monteiro and Silva<sup>19</sup>, represented an important advance.

Lima<sup>17</sup> states that, if the living will was prepared at the time when the person was conscious of their actions and was able to discern about their will, preceding a state of terminality, the family and professionals must recognize and respect the autonomy of this patient.

## Final considerations

This review approached the lack of consensus in the legal sphere due to the lack of regulation establishing clear rules for the preparation of a Brazilian model of advance directives that can be attached to the patient's medical record. Thus, it is considered that it is not enough to guarantee that individuals have the right to express their will, it is also necessary to ensure that it will be fulfilled, and to provide security on the part of the health professionals involved, family members and patients.

In addition, it is essential that professionals have full knowledge of the subject to inform and instruct their patients correctly. Therefore, it is necessary to expand discussions on the subject, with emphasis on the Brazilian reality.

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