



## RESEARCH

# Living will: information verification and sharing in a Portuguese hospital

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## Abstract

The Living Will constitutes, since 2012, a legally protected right in Portugal. This exploratory-descriptive study questioned physicians and nurses from a Portuguese hospital regarding the verification and sharing of information related to the Living Will. Most professionals (57%) have never verified the existence of a Living Will, although they consider this an important action (95%) and share this information when they have access to it (82%), considering that not sharing has important implications for care practice (86%). The results show that verifying the existence of a Living Will does not constitute a current practice in the studied hospital. Further research is necessary to identify the underlying motivations for such behavior and investigate the dimension of this reality in other health institutions, proposing measures to promote professional practice consistent with that established by law.

**Keywords:** Advance directives. Patient centered-care. Ethics, medical. Ethics, nursing.

## Resumo

### Testamento vital: verificação e compartilhamento de informações em um hospital português

Desde 2012, o testamento vital é direito legalmente protegido em Portugal. Este estudo, exploratório-descritivo, questionou médicos e enfermeiros de um hospital português sobre verificação e compartilhamento de informação relativa ao testamento vital. A maioria dos profissionais (57%) nunca verificou a existência do documento, embora considere ato importante (95%), compartilhe essa informação quando tem acesso a ela (82%) e julgue que o não compartilhamento tem implicações relevantes na prática de cuidados (86%). Os resultados mostram que verificar a existência de testamento vital não é, no hospital estudado, prática corrente. São necessários novos estudos que identifiquem as motivações subjacentes a esse comportamento e verifiquem se é comum em outras instituições de saúde, propondo medidas para promover prática profissional em consonância com o estabelecido pela lei.

**Palavras-chave:** Diretivas antecipadas. Assistência centrada no paciente. Ética médica. Ética em enfermagem.

## Resumen

### Testamento vital: verificación e intercambio de informaciones en un hospital portugués

Desde 2012, el testamento vital constituye un derecho legalmente protegido en Portugal. Este estudio, exploratorio-descriptivo, interrogó a médicos y enfermeros de un hospital portugués sobre la verificación y el intercambio de informaciones respecto del testamento vital. La mayoría de los profesionales (57%) nunca verificó la existencia del documento, aunque consideran a éste un acto importante (95%), comparten esta información cuando tienen acceso a ella (82%), y consideran que no compartirla tiene implicancias importantes en la práctica de cuidados (86%). Los resultados muestran que verificar la existencia del testamento vital no constituye, en el hospital estudiado, una práctica corriente. Son necesarios nuevos estudios que identifiquen las motivaciones subyacentes a tales comportamientos y verifiquen si es común en otras instituciones de salud, proponiendo medidas para promover una práctica profesional en consonancia con lo establecido por la ley.

**Palabras clave:** Directivas anticipadas. Atención dirigida al paciente. Ética médica. Ética en enfermería.

Declaram não haver conflito de interesse.

The right to health protection, established as fundamental in the 20th century<sup>1</sup>, was an important achievement of civilizations in general. Increasing access to health care, coupled with the development of biomedical sciences and better living conditions, especially from the second half of the century, optimized the health of individuals, significantly increasing the average life expectancy<sup>2</sup>.

This ability to add time to life has become a collective effort to postpone death at all costs, alienating health care from the lives and will of patients and causing avoidable suffering. Thus, in societies structured under the aegis of human dignity, the question arises as to how far some interventions can go beyond the limits of what is considered ethically acceptable<sup>3</sup>.

The social awareness that health care should be more humanized, holistic and centered in the person and his or her will at any stage of the life cycle has brought to public discussion issues such as equal access, quality of care and patient autonomy. Regarding the latter, the requirement for informed consent and, subsequently, the living will, were probably the biggest outcome from the discussion<sup>4</sup>.

The Advance Directive (AD) is a document of prior expression of decisions for medical treatment, written by a capable person, in full exercise of their autonomy, in order to safeguard respect for their health options in the event of incapacity or impossibility to express themselves. The living will is a form of AD and consists of a document written by the individual, in which he or she makes known the choices they want to see respected. Another modality is the health care proxy, where the patient appoints a person responsible for taking decisions if he or she is unable to do so<sup>5</sup>.

The living will was originally legalized in the United States in the 1990s and later integrated into the legal system of other countries in the Americas and Europe. In Brazil, there is still no specific legislation regarding the subject, although the Conselho Federal de Medicina (CFM) (Brazilian Federal Council of Medicine) approved, in 2012, Resolution 1,995, which recognizes the right of patients to express their will regarding medical treatment or to appoint a representative for this purpose, as well as the duty of the physician to fulfill this will<sup>5-7</sup>. However, the document has no

legal power, although today legislative initiatives on this matter already exist.

In Portugal, the growing need to adapt the legal situation to the social situation culminated in 2006 in the presentation, by the Portuguese Bioethics Association, of the first bill on living wills<sup>8</sup>. The Code of Ethics of the Medical Association itself, which, in its 1985 version<sup>9</sup>, attributed to medical care the main objective of curing the disease and prolonging life, was changed in 2008 to recognize the provision of care to patients without hope of cure or in the terminal phase and to respect the AD<sup>10</sup>.

In 2012 Law 25/2012, the first in Portugal regarding living wills, was finally passed. Article 2, paragraph 1 of this decree-law defines the AD, in the form of a living will, as *a unilateral document which is freely revocable at any time by itself, in which a legal aged and capable person (...) expresses in advance their conscious, free and informed will, in regard to the health care they wish to receive, or do not wish to receive, in case, for any reason, they are unable to express their will personally and autonomously*<sup>11</sup>. Thus, it is clear that the health team should respect the content of the document, except in certain situations provided for by law (note, for example, that the living will is valid for five years) or, in urgent cases, when diligence for accessing the document might severely impair the patient's condition<sup>11</sup>.

The statute also regulates the appointment of a health care proxy and creates the Registo Nacional do Testamento Vital - Rentev (National Registry of Living Wills), a nationwide database that *centralizes and keeps living wills (LW) up to date, ensuring consultation with citizens (and their health care proxy, if any) (...) and with physicians responsible for healthcare*<sup>12</sup>, whether from the National Health Service or from the private sector. RENTEV registration *has a declarative value only*, and what is described in the document has equal value, as long as it has been formalized according to law<sup>11</sup>.

This statement may be given to physicians by patients themselves or by health care proxies. If this does not occur, the attending physician, in front of a patient unable to freely and autonomously express his or her wishes, should identify criteria that require consultation with RENTEV, such as adulthood and prior ability - that is, indicators of the possibility that the patient, at some point in the last five years, in the exercise

of his or her autonomy, has written a living will. In this context, nurses are also fundamental to ensure not only the care, but also the patients' autonomy, responding to their needs or arranging other professionals when these needs go beyond their field of competence<sup>13</sup>.

Portuguese law exclusively grants physicians the right of access to Rentev, making nurses dependent on physicians sharing information regarding the existence and content of the living will (even though the law binds the entire health team to the provisions of this document). This lack of knowledge can lead to conduct by the nursing staff that go against what is stipulated in legal and ethical documents.

Therefore, it is important to understand if the legal status of the AD has made effective the exercise of individual autonomy in health matters in Portugal, considering that, in this context, professionals assume a pivotal role that goes from planning to realization of the will. Given the lack of Portuguese studies focused on the practice of health professionals in this regard, this study sought to identify the attitudes and conduct of physicians and nurses of a Portuguese hospital regarding the verification and sharing of information concerning living wills, specifically in the case of patients without the ability to exercise their autonomy.

## Method

An exploratory, descriptive, cross-sectional study with a quantitative approach was developed in 16 inpatient services of a hospital from the Portuguese national health service network, which is a public and universal system. The study population included physicians and nurses working in these services, which is the only requirement for inclusion, obtained by accidental sampling technique (professionals who were in service during the distribution of questionnaires), totaling five physicians and five nurses per service. The study took place over a period of four months (November 2017 to February 2018).

Data were collected through two self-completed questionnaires specifically designed for this study: one directed to physicians (Questionnaire 1) and another to nurses (Questionnaire 2). Composed of two groups of questions, they first sought to characterize the groups in relation to attributes of potential interest to the study, coinciding the variables. In the second part, attitudes and conduct related to the verification and sharing of information regarding living wills in the case of patients without the ability to exercise autonomous decisions, with questions addressed to each group, in order to evaluate non-shared variables of interest (Table 1).

**Table 1.** Variables analyzed in the questionnaires

Part I	
Q1	Age
Q2	Gender
Q3	Academic/professional qualifications
Q4	Years of professional experience
Q5	Service
Q6	Period of working in this function in the current service
Part II – Questionnaire 1	
Q1	Attribution of importance to the act of verifying the existence of a living will in the case of patients without the ability to exercise autonomous decisions.
Q2	Point in time, since hospital admission, that is considered the most appropriate to verify the existence of a living will in the case of patients without the ability to exercise autonomous decisions.
Q3	Point in time that is considered the most appropriate to verify the existence of a living will in the case of patients that lose the ability to exercise autonomous decisions while hospitalized.
Q4	Frequency of verifying if there is a living will in the case of patients without the ability to exercise autonomous decisions.
Q5	Sources used to verify the existence of a living will in the case of patients without the ability to exercise autonomous decisions.
Q6	Usefulness attributed to the National Registry of Living Wills (Registo Nacional do Testamento Vital - RENTEVE) in verifying the existence of living wills.
Q7	Existence of difficulties (and their nature) when consulting RENTEVE.
Q8	Existence of practical implications (and their nature) arising from lack of knowledge regarding the existence of a living will.
Q9	Importance given to the act of sharing, with other health professionals, information about the existence of a living will.

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**Table 1.** Continuation

Part II – Questionnaire 1	
Q10	Frequency of sharing information regarding the existence of a living will.
Q11	Existence of practical implications (and their nature) arising from the option of not sharing information regarding the existence of a living will.
Parte II – Questionário 2	
Q1	Attribution of importance to the act of verifying the existence of a living will in the case of patients without the ability to exercise autonomous decisions.
Q2	Means of becoming aware of the existence of a living will in the case of patients without the ability to exercise autonomous decisions.
Q3	Sources used to verify the existence of a living will in the case of patients without the ability to exercise autonomous decisions.
Q4	Atribuição de importância ao ato médico de partilhar com a equipe de enfermagem informação relativa à existência de testamento vital.
Q5	Sharing information regarding the existence of a living will.
Q6	Existence of practical implications (and their nature) arising from the medical option of not sharing with the nursing team information regarding the existence of a living will.

Each questionnaire contained information about the research and the declaration of consent to participate in the study. The documents were collected while they were being filled in or afterwards, according to the respondents' preference. The data obtained were treated with the Statistical Package for the Social Sciences (SPSS, version 20.0, IBM, Armonk, NY), independently for each group.

As for the open questions, the answers were categorized before data entry into the statistical analysis program. Descriptive analysis of variables was performed, with calculation of absolute and relative frequencies. To evaluate possible associations between variables, the chi-square independence test was used, or Fisher's test, if the requirements for the first one were not met. For statistically significant results ( $p < 0.05$ ), the intensity of the association was evaluated by Cramer's V test or by the phi test for 2 by 2 input tables.

### Ethical considerations

This study was designed to ensure the fundamental rights and freedoms of participants, respecting the provisions of the *Helsinki Declaration*<sup>14</sup> and the *Belmont Report*<sup>15</sup>. The research protocol and all documents used during the research were approved by the Hospital Ethics Committee and respective board of directors. The service directors and heads of nursing were consulted prior to the implementation of the study to obtain their authorization. The questionnaires were coded and separated from the consent forms after completion. The codification intended to ensure the right of dissent in the subsequent phases of the research.

### Results

The study included 126 participants, of which 60 were physicians and 66 were nurses, with a response rate of 75% and 82.5%, respectively. The characterization of the sample is summarized in Table 2. No association was found between demographic characteristics and the variables studied.

**Table 2.** Sample characterization

	Physicians n (%)	Nurses n (%)
<b>Gender</b>		
Male	36 (60,0)	23 (34,8)
Female	24 (40,0)	43 (65,2)
<b>Age group (years)</b>		
25-35	28 (46,7)	31 (47,0)
36-45	14 (23,3)	27 (40,9)
46-55	10 (16,7)	5 (7,6)
>55	8 (13,3)	3 (4,5)
<b>Years of professional experience</b>		
≤5	18 (30)	5 (7,6)
6-10	12 (20)	11 (16,6)
11-20	13 (21,7)	38 (57,6)
>20	17 (28,3)	12 (18,2)
<b>Period of working in the current service (years)</b>		
<1	9 (15)	4 (6,1)
1-5	13 (21,7)	11 (16,6)
6-10	12 (20)	24 (36,4)
11-20	16 (26,7)	24 (36,4)
>20	9 (15)	3 (4,5)

continues...

**Table 2.** Continuation

	Physicians n (%)	Nurses n (%)
<b>Academic/professional qualifications</b>		
Secondary education	1 (1,7)	32 (48,5)
Integrated master	15 (25)	–
Post-graduation	–	8 (12,1)
Master pre-Bologna	–	4 (6,1)
Specialization	44 (73,3)	22 (33,3)
Doctorate	5 (8,3)	–

### Results of Questionnaire 1 (Part II)

Of the 60 physicians surveyed, 93% (n=56) consider that, in the case of patients without the ability to exercise autonomous decisions, it is important to verify the existence of a living will. For 5% of these (n=3), such importance is found only in certain situations - for example, in cases of legal aged patients (n=1), poor prognosis (n=2), organ transplantation (n=1), or absence of a legal representative (n=1).

Most participants answered that the most appropriate time for this verification would be on admission, both in the case of patients who could not exercise their autonomy since hospital admission (75%; n=45) and in the situation in which they lose this capacity during hospitalization (67%; n=40). For a smaller portion of the sample, the most favorable point varies according to the circumstances: in the first case, for 20% (n=12) other situations would be more appropriate, especially when there is a risk of death and a poor prognosis (n=5), or in a decision-making moment (n=2); in the second, for 25% (n=15), the most appropriate phase would be from loss of capacity (n = 5) and in situations of clinical instability, poor prognosis and risk of death (n=4), or in a decision-making moment (n=2).

A positive association was observed between assigning importance to the verification of the existence of a living will and choosing the moment of admission as the most pertinent, in the first case (Cramer's  $V=0.509$ ;  $p=0.000$ ) and in the second case (Cramer's  $V=0.414$ ;  $p=0.008$ ).

As for the verification procedure, 63% (n=38) of the sample never performed it, and only 7% (n=4) do it routinely; 8% (n=5) follow this check only in certain circumstances, including: cases of poor prognosis (n=2), lack of communication with family members (n=1) and need for invasive measures (n=1). Among

the participants who follow the procedure, we have as sources of information: family members or significant cohabitants (32%; n=7), RENTEVE (14%; n=3) or both (41%; n=9).

In fact, 78% (n=47) of respondents have never consulted RENTEVE, and among those who have already done such consultation (20%; n=12), 33% (n=4) encountered difficulties, claiming difficult or restricted access (n=1), lack of information or time to access the platform (n=2), or lack of some AD records (n=1), suggesting that this information should be printed on physical media (n=1), be accessible in the medical record program (n=1), or have more information on the topic (n=1).

Rentev is still considered a useful tool by 48% of participants (n=29), but 45% (n=27) have no opinion on the subject. On the other hand, 7% (n=4) do not consider it useful, pointing out as reasons the lack of knowledge about the tool (5%; n=3), the difficulty of usage and questionable reliability (1.6%; n=1). When there is a living will, most of the sample (88%; n=53) considers it important to share this information, and that its omission has practical implications (85%; n=51), with a positive association between the two responses (Cramer's  $V=0.530$ ;  $p=0.001$ ). Among the consequences mentioned are the risk of disrespecting the patient's will (n=18); the loss of uniformity among team practices (n=6); the provision of inadequate/excessive care (n=9); ethical-legal consequences (n=3); and change in treatment (n=1).

Likewise, there is an association between the importance of verifying the living will and the sharing of this information (Cramer's  $V=0.617$ ;  $p=0.000$ ), as well as between this and the importance attributed to it (Cramer's  $V=0.530$ ;  $p=0.001$ ). The professional groups most commonly referred to as sharing targets are physicians (n=7), nurses (n=2), physicians and nurses (n=18), physicians and social workers (n=1), or all the professionals who provide care to the patient (n=15).

Still, only 50% (n=30) of participants always disclose this information, and 30% (n=18) sporadically, but 20% (n=12) declare not doing so. In the case of those who share it, this is done through medical records (n=10), oral communication (n=8), or both (n=22).

Finally, 77% (n=46) of respondents consider that there are practical implications in not knowing whether or not the patient has a living will. In this context, respondents mention, above all, acts that may undermine the will of patients or disrespect their autonomy (n=21); consequences on decision making and therapeutic orientation (n=8); ethical

or legal implications (n=6); provision of inadequate, excessive or dehumanized care (n=4); disrespect for patients' situations (n=1); possible conflicts with patients' families or legal representatives (n=1); and incompatible practices among team members (n=1).

An association was found between the importance attributed to verifying the existence of a living will and the opinion about the implications of not knowing of its existence. Participants who answer affirmatively to the first question tend to also agree with the second question - as in the case of a negative answer (Cramer's  $V=0.496$ ;  $p=0.001$ ).

### Results of Questionnaire 2 (Part II)

From the total of 66 nurses, 97% (n=64) consider that, in the case of patients without the ability to exercise autonomous decisions, the health team should always verify the existence of a living will, but 3% (n=2) believe that this verification should be done only when the family cannot decide for the patient (n=1), or in case of poor prognosis (n=1). Still, 52% (n=34) of respondents have never checked such information. Those who do verify it (n=32) use one or more sources: medical records (88%; n=28); family members or significant cohabitants (78%; n=25); physicians (38%; n=12); and able patients, when loss of autonomy occurs during hospitalization (9%; n=3).

The majority (74%; n=49) of the sample state that they never knew about this will. The means by which the rest of the participants (26%; n=17) got to know about the document were: family members or significant cohabitants (n=10); physicians, verbally (n=5) or via medical records (n=3); or able patients, when the loss of autonomy occurred during hospitalization (n=1).

Once the existence of the living will is known, 83% (n=55) would share this information. Of these, 20% (n=11) would only do so with a professional group: physicians (n=10) or nurses (n=1). A larger portion (71%; n=39) would share the information with more professional categories, of which the following were the most represented in this group of answers: physicians (n=37), nurses (n=34) and others, such as physiotherapists, dietitians, etc. (n=24).

Respondents generally consider (94%; n=62) that it is important for the physician to disclose to the nursing team information regarding the existence of a living will, referring to nurses' role in the multidisciplinary team (n=19) and in care giving (n=9), or claiming that the planning of individualized and humanized care (n=10), the

implementation of practices that comply with the patient's will (n=16) and the conduct in emergency situations (n=5) depend on it.

Finally, 86% (n=57) consider that the medical option of not sharing information regarding this will has important implications, hampering the fulfillment of the patient's will (n=21); care planning and decision-making (n=11); the uniformity of the team work (n=6); the adequacy and humanization of care (n=9); the relationship with the patient's family or others (n=4); ethical and legal principles (n=3); and the speed in obtaining information (n=1). Participants who consider these consequences tend to exchange living will information when they become aware of it ( $\phi=0.389$ ;  $p=0.011$ ).

### Discussion of results

The survey results allowed identifying among the respondents the predominance of favorable attitudes towards the living will. Most participants recognize the importance of verifying that the patient has the document (95%) and, if so, sharing their information (91%). Still, there is discrepancy between attitudes and conduct, considering that, while most physicians and nurses (82%) share information regarding living wills, more than half still fail to confirm the existence of the document (57%).

Law 25/2012, in force in Portugal, provides that, in cases of patients without the ability to exercise their will in a free and autonomous manner, the physician is responsible for verifying, in consultation with RENTEV, the registration of an AD document or healthcare power of attorney<sup>11</sup>. However, analysis of the results showed that most interviewed physicians (78%) have never consulted Rentev.

Similarly, the law provides that if a physician becomes aware of an AD or healthcare power of attorney, he or she must attach these documents to the patient's medical records<sup>11</sup>, which is seen by physicians as the primary means of sharing information and by nurses as the primary resource to prove the existence of a living will.

The law states that, once this patient's will is known, the health team should respect its content<sup>11</sup>. Following this line of thought, most participants agreed on the important ethical and legal implications of not knowing of the document or not sharing information concerning it, and expressed concern on this matter.

As in the present study, Velasco-Sanz and Rayón-Valpuesta<sup>16</sup> identified incongruities between (positive) attitudes and (negative) conduct regarding the living will among physicians and nurses in nine Madrid hospitals, concluding that 90.6% did not verify the existence of the document, although they recognized its usefulness. The same study also identified limited knowledge on the subject.

In fact, several studies have pointed to a lack of knowledge regarding living wills among health professionals, as opposed to positive attitudes towards the document<sup>16-19</sup>, with a direct relationship between the level of knowledge and characteristics such as previous experience and academic education<sup>18,19</sup>. Likewise, procedures that do not comply with end-of-life legislation have already been associated with a lack of familiarity with these legal principles<sup>20</sup>.

In the present study, neither knowledge about the living will or its legislation nor the professional experience of the participants was assessed, so no conclusions can be drawn in this area. However, there are two results that seem to suggest a lack of nursing professionals' experience and a shortage of living will knowledge among physicians. These are: the fact that 74% of the interviewed nurses had never become aware of such a document; and that 45% of physicians did not have an opinion about RENTEV, which confirms the result of a study conducted in Portugal in 2017, which identified, among health professionals in a hospital unit, the need for training on the subject of ADs<sup>21</sup>. On the other hand, no association was found between variables related to participants' attributes, and their attitudes and conduct in relation to the living will, although it has been shown that participants with positive attitudes tend to behave in accordance with the law.

Finally, regarding the best situation to verify the existence of a living will, most participants considered that it would be when the patient is admitted, but part of the sample referred to the need for verification in specific circumstances, especially

related to imminent life-threatening contexts or poor prognosis. No previous studies exploring this topic were found, nor is the law clear in this regard. From its reading it can be inferred that, in the case of patients without autonomous decision-making ability, the procedure must happen at the moment of admission, but, as regards patients who lose their autonomy during hospitalization, it is not possible to draw conclusions.

Nevertheless, it is of utmost importance to remember the inconsistency of health conditions and the possibility of any patient admitted to an inpatient unit to suddenly and unexpectedly lose their autonomy and have their prognosis altered. This risk requires one to consider whether it would be preferable to have prior knowledge of the advance directive document existence in all cases of hospitalization<sup>22</sup>. One possible solution would be to inform all patients during the hospital admission process of the existence, scope and limits of the AD<sup>23</sup>.

### Final considerations

Confirming the existence and sharing of information regarding living wills is a key element in putting it into practice. The results of this research show that checking for an AD document is not common practice in the professional group studied. Further studies are needed to identify the reasons behind such behavior, and whether the reality described here is the same as that of other health institutions. Research of this kind would allow the adoption of strategies to promote professional practice appropriate to the ethical and legal frameworks for end-of-life care. Implementing health education strategies that increase the knowledge of professionals about the existence, scope and limitations of advance directives is a priority axis of public policy, both in Portugal and in Brazil, where the approval of legislation regarding living wills is anticipated.

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#### Participation of the authors

Carla Ferreira conceived the project, collected and processed the data and wrote the manuscript. Rui Nunes guided and supervised the project, undertook the critical review of the manuscript and approved it for publication.

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