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# Knowledge of medical students regarding living wills

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## Abstract

The end of a person's life raises many ethical dilemmas. Recently, the Brazil's Federal Council of Medicine approved and regulated the concept of "living will"; as a result, it is of considerable importance that doctors understand the issues that surround this matter. The aim of the present study was to evaluate the knowledge of medical students from the Pará State University, Brazil, of "living wills" and decisions involving the end of life. A cross-sectional study was performed with 238 students who answered a questionnaire of 10 questions. Only 8% of students demonstrated a clear understanding of the term "living will". Nevertheless, when the definition of "living will" was explained to the participants of the study by the researchers, 92% of students declared that they would respect its provisions. Therefore it appears that while most respondents had a low level of understanding of the concept of "living will", the vast majority positioned themselves in favor of accepting such a document.

**Keywords:** Knowledge. Living wills. Patient rights-Right to die. Advance directives. Advance directive adherence. Students, Medical. Education.

## Resumo

### Conhecimento de estudantes de medicina sobre o testamento vital

A terminalidade da vida levanta cada vez mais dilemas éticos. Dada a importância do tema e a recente regulamentação do testamento vital pelo Conselho Federal de Medicina, é de grande valor o conhecimento dessa problemática por parte dos futuros médicos. Assim, buscou-se aferir a compreensão dos estudantes de medicina da Universidade do Estado do Pará acerca do testamento vital e das decisões envolvendo o final da vida. O estudo qualitativo descritivo e transversal entrevistou 238 estudantes por meio de questionário com 10 questões. Apenas 8% dos estudantes demonstraram ter uma noção clara sobre o significado do termo "testamento vital". Apesar disso, após ouvirem a definição das diretivas antecipadas de vontade fornecida pelos pesquisadores, 92% deles declararam que respeitariam o previsto no testamento vital. Portanto, conclui-se que, embora boa parte dos entrevistados tenha pouco entendimento sobre o tema "testamento vital", a grande maioria posicionou-se a favor de sua aceitação.

**Palavras-chave:** Conhecimento. Testamentos quanto à vida. Direitos do paciente-direito a morrer. Diretivas antecipadas. Adesão a diretivas antecipadas. Estudantes de medicina. Educação.

## Resumen

### El conocimiento de los estudiantes de medicina sobre testamento vital

La terminalidad de la vida levanta cada vez más dilemas éticos. Dada la importancia del tema y la reciente regulación del testamento vital por el Consejo Federal de Medicina del Brasil, es de gran valor el conocimiento de los futuros médicos acerca de este problema. Por lo tanto, tratamos de evaluar el conocimiento de los estudiantes de medicina de la Universidad del Estado del Pará, en Brasil, acerca del testamento vital y de las decisiones que involucran el final de la vida. La muestra del estudio cualitativo y cuantitativo descriptivo y transversal entrevistó 238 estudiantes y utilizó cuestionario con 10 preguntas. Sólo el 8% de los estudiantes han demostrado una clara comprensión sobre el término "testamento en vida". Sin embargo, después de escuchar la definición de directrices anticipadas de voluntad proporcionada por los investigadores, el 92% del total declaró que respetarían las disposiciones del testamento vital. Por lo tanto, parece que la mayoría de los encuestados tienen un bajo nivel de comprensión del tema del "Testamento Vital", pero la gran mayoría se ha posicionado a favor de la aceptación.

**Palabras-chave:** Conocimiento. Voluntad en vida. Derechos del paciente-derecho a morir. Directivas anticipadas. Adhesión a las directivas anticipadas. Estudiantes de medicina. Educación.

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Declararam não haver conflito de interesse.

The terminal phase of a disease raises a growing number of ethical dilemmas, generating conflicts among health professionals, patients and family members <sup>1</sup>. When an illness becomes terminal, therapeutic measures can no longer increase the patient's chances of survival, and instead merely prolong the process of dying <sup>2</sup>.

In order to alleviate the pain inherent in the terminal phase of an illness, three approaches are usually defined: euthanasia, orthothanasia and dysthanasia. Euthanasia, or the "good death", is a practice designed to prevent the suffering of the patient from extending to the end of his or her life <sup>3</sup>. Dysthanasia is a form of therapeutic obstinacy, aimed at delaying an inevitable death. Orthothanasia, meanwhile, treats death as a natural process, in which patients receive treatment only to eliminate or lessen their pain and suffering <sup>4,5</sup>.

However, until recently, people with terminal illnesses who found themselves in a vulnerable situation, with a loss of cognitive, mental and relationship capacity, could not decide what kind of medical treatment they would receive. In such cases, any decision regarding treatment was up to the legal representative of the patient. In order to preserve patient autonomy, a significant number of countries (Mexico, Argentina, Colombia, Bolivia and several states of the United States) have incorporated into legislation the concept of "advance healthcare directives", previously called a "living will". This is a document written by a person in full possession of their mental faculties, the purpose of which is to specify the care, treatment and procedures which they want, or do not want, to receive when affected by serious illness and are unable to freely express their will <sup>6</sup>.

The living will was first proposed in 1967 by the then American Society of Euthanasia as a document relating to anticipated care. In this document, an individual could express in writing his or her desire to suspend medical procedures aimed at the maintenance of life. But it was only in 1991 that a legal provision on the subject was approved: the Patient Self Determination Act (PSDA), the first US federal law to recognize the right to the self-determination of the patient <sup>7</sup>.

In Europe, the first country to legalize advance healthcare directives was Spain in 2002. In Portugal, official debate on the subject only began in 2006, based on the proposal of the *Associação Portuguesa de Bioética* (Portuguese Bioethics Association), which was submitted to the Comissão de Saúde da

Assembleia da República (Health Commission of the Portuguese Parliament). According to Nunes <sup>8</sup>, a bill on informed consent was presented in 2009. While this bill originally proposed the legalization of advance healthcare directives, this topic has since been removed. It was only in July 2012 that the Portuguese Parliament enacted Law 25, which *governs advance healthcare directives such as living wills and the appointment of a health care proxy and creates the Registro Nacional do Testamento Vital (National Living Will Registry)* <sup>9</sup>. In Argentina, where discussion of the topic remains on the political agenda, the first legislation on advance healthcare directives was Law 4263, in the province of Río Negro, enacted on December 19, 2007 <sup>10</sup>.

In Brazil, no individual is prevented from notarizing their will in relation to the medical care desired in case of incurable disease. However, with respect to the bioethical principle of autonomy, which expresses the individual's free will, there is no legislation that requires medical practitioners to comply with the patient's wishes in a terminal situation. As a result, this right is little known and observed by society. However, on August 31, 2012, the *Conselho Federal de Medicina* (CFM - Federal Council of Medicine) published Resolution 1995, which governs advance healthcare directives (living wills) <sup>11,12</sup>. From this moment onwards, doctors have been obliged to respect the wishes of terminally ill patients, unless those desires (or the desires of their legal representatives) are in conflict with the precepts of the *Código de Ética Médica* (CEM - Code of Medical Ethics) <sup>13</sup>. According to this resolution, the advance healthcare directives of patients prevail over any other non-medical opinion, including the wishes of relatives <sup>11</sup>.

Medicine is currently undergoing a period in which a sensible balance in the doctor-patient relationship is sought. Traditional medical ethics were marked by a strong paternalistic instinct, where the patient would simply comply with the medical decisions made for him or her. Thus, until the first half of the twentieth century, any medical act was judged by taking into account only the morality of the agent, without considering the values and beliefs of patients. It was only in the 1960s that professional codes of ethics came to recognize the patient as an autonomous agent <sup>14</sup>.

Whether because of the significance of the decisions of the patient regarding the healing process and diagnostic and therapeutic actions, particularly with regard to future medical conduct, or by the

regulating of this issue by the CFM<sup>11,15</sup>, knowledge of advance healthcare directives and their consequences for the patient is now of vital importance to medical students. The issue is therefore of great relevance to both professionals and patients, manifesting itself both as a concern for the autonomy of patients and part of any consideration of the future of the medical profession and its relationship with the attitudes and aspirations of society. The aim of this study was therefore to determine the level of knowledge of medical students regarding the subject of living wills.

## Method

The present work took the form of a descriptive qualitative and quantitative cross-sectional study. A total of 238 medical students from the *Universidade do Estado do Pará* (UEPA - Pará State University), in the 1<sup>st</sup> to the 8<sup>th</sup> semester of study, were surveyed during the month of September 2013. All medical students in this group were included in this study, subject to the exclusion criteria, which were: (1) students under 18; (2) students who refused to participate in the interview or to sign the “termo de consentimento livre e esclarecido” (TCLE - free and informed consent form), which described in detail the objectives of the study.

The research instrument was a questionnaire designed specifically for the study (Appendix 1). This consisted of ten questions, four to classify the respondents into groups (age, gender, current semester of course, religion), an objective question on behavior when treating a terminally ill patient (dys-thanasia, euthanasia or ortho-thanasia) and an open question in which the interviewee talked about what he or she understood by the term “living will”. After this question the interviewees were given a definition of “living will” before answering the 7<sup>th</sup> question, which was whether they would or would not accept the living will of a patient in the final phase of life. The three last questions asked about: whether the student had come into contact with the term “living will” during his or her university course (8<sup>th</sup>); knowledge of the existence of Resolution 1.995 (9<sup>th</sup>), and the source of this knowledge (10<sup>th</sup>).

The question in which the student discussed the living will was analyzed using the “discurso do sujeito coletivo” (discourse of the collective subject - DSC), which sought to ascertain whether the respondent had a clear or partial notion of, or was

not aware of, the theme. When applying the questionnaires to the students, the researchers provided instructions collectively, in the classroom, explaining the objectives and the form of the participation of individuals in the study. At this time, the TCLE was provided and the optional nature of participation in the study was stressed, together with a reminder that the questionnaire should be filled out individually and without consulting external bibliographic references.

All the subjects in the study were treated in accordance with the precepts of the *Declaration of Helsinki*<sup>16</sup> and the *Nuremberg Code*<sup>17</sup>, and the guidelines and directives governing research involving humans expressed in Resolution 466/2012 of the Federal Council of Medicine were respected<sup>18</sup>. The study was approved by the *Núcleo de Pesquisa e Extensão de Medicina* (NUPEM - Center for Medical Research and Extension Studies) and the research supervisor of the work.

The Excel 2007 software program was used to process the quantitative data, and from a qualitative perspective, the table from the study by Piccini et al.<sup>19</sup> (Appendix 2) was used to analyze the DSC. The Word 2007 software program was used to prepare the text. Descriptive statistical analysis was performed, based on the absolute and percentage values studied.

## Results

Of the 238 students interviewed, 108 were men (45.3%) and 130 were women (54.7%). Of these, 45 (19%) were in the first two semesters of their course; 63 (26%), in the 3<sup>th</sup> or 4<sup>th</sup> semester; 68 (29%), in the 5<sup>th</sup> or 6<sup>th</sup> semester, and 62 (26%), in the 7<sup>th</sup> or 8<sup>th</sup> semester.

The age of the students varied between 17 and 28 years. In the first two semesters, the majority (82%) were between 17 and 20 years. In the 3<sup>rd</sup> and 4<sup>th</sup> semesters, 57% were aged between 17 and 20 years. In the 5<sup>th</sup> and 6<sup>th</sup>, the age groups 17 to 20 years (48%) and 21 to 24 years (44%) were almost equal. In the last two semesters, the majority of respondents (79%) were aged between 21 and 24 years.

In terms of understanding of the term “living will”, only 6% of respondents demonstrated a clear notion, while 33.1% of respondents had a partial notion, 11% were unaware of the theme and the great majority (50%) refrained from answering the question (Table 1).

**Table 1.** Understanding of UEPA medicine students in the 1st to the 8th semester of study, in September 2013, of the term “living will”

Understanding/ Semester	1st- 2nd n (%)	3rd- 4th n (%)	5th- 6th n (%)	7th- 8thn (%)
Clear	5 (11)	5 (8)	2 (3)	7 (11)
Partial	14 (31)	16 (23)	20 (29)	18 (29)
Unaware	10 (22)	11 (17)	3 (4)	2 (3)
“Nothing to declare”	16 (36)	31 (52)	43 (64)	35 (57)
<b>Total</b>	<b>45 (100)</b>	<b>63 (100)</b>	<b>68 (100)</b>	<b>62 (100)</b>

When asked about the possibility of treating a terminally ill patient with a living will, 43 of students (95%) from the 1<sup>st</sup> and the 2<sup>nd</sup> semesters, 62 (98%) from the 3<sup>rd</sup> and 4<sup>th</sup>, 64 (94%) from the 5<sup>th</sup> and the 6<sup>th</sup> and 60 (97%) from the 7<sup>th</sup> and 8<sup>th</sup> semesters, stated that they would respect the wishes of the patient (Table 2).

**Table 2.** Position of UEPA medicine students in the 1st to the 8th semester of study, in September 2013, regarding the possibility of treating a terminally ill patient with a living will

Position/ Semester	1st- 2nd n (%)	3rd- 4th n (%)	5th- 6th n (%)	7th- 8thn (%)
Would respect	43 (95)	62 (98)	64 (94)	60 (97)
Would not respect	2 (5)	1 (2)	4 (6)	2 (3)
<b>Total</b>	<b>45 (100)</b>	<b>63 (100)</b>	<b>68 (100)</b>	<b>62 (100)</b>

In terms of the knowledge of the respondents about CFM Resolution 1.995/2012, the great majority (29%) said that they were unaware of such resolution. Only six (15%) students from the 1<sup>st</sup> and the 2<sup>nd</sup> semesters, 21 (33%) from the 3<sup>rd</sup> and 4<sup>th</sup> semesters, 24 (35%) from the 5<sup>th</sup> and 6<sup>th</sup> and 20 (32%) from the 7<sup>th</sup> and 8<sup>th</sup> semesters possessed some knowledge of the subject. All those who declared they knew about the resolution said in the questionnaire that they had obtained their information from the university itself.

Only a small number (18%) of students from the first two semesters said they had had the opportunity to discuss the theme of “living will” during

their course. This percentage varied in subsequent semesters, with 66% of students in the 3<sup>rd</sup> and 4<sup>th</sup> semesters, 53% from the 5<sup>th</sup> and 6<sup>th</sup> and 45% from the 7<sup>th</sup> and 8<sup>th</sup> having had such a discussion (Table 3).

**Table 3.** Distribution of students in the 1st to the 8th semester of the UEPA medicine course, in September 2013, who had had the opportunity to discuss the subject of the “living will” as part of their degree

Opportunity/ Semester	1st- 2nd n (%)	3rd- 4th n (%)	5th- 6th n (%)	7th- 8thn (%)
Discussed	8 (18)	42 (66)	36 (53)	28 (45)
Had not discussed	37 (82)	21 (34)	32 (47)	34 (55)
<b>Total</b>	<b>45 (100)</b>	<b>63 (100)</b>	<b>68 (100)</b>	<b>62 (100)</b>

## Discussion

In the medicine course at UEPA, the first (and only) curricular contact of students with themes of bioethics occurs in the 3<sup>rd</sup> or 4<sup>th</sup> semester, in the discipline of Medical Ethics and Human Rights. Despite the fact that issues relating to bioethics are an essential part of medical practice, it can be seen that this area is largely absent from the training of future medical professionals.

When questioned, only 8% of students demonstrated a clear notion of the meaning of the term “living will”. Of these, 74% were in at least their 3<sup>rd</sup> semester. In contrast, 64% of those interviewed from the 3<sup>rd</sup> to the 8<sup>th</sup> semester chose the option “Nothing to declare” or revealed that they were not aware of the term. As Hossne and Hossne have observed, medicine courses, in general, deal with the subject of bioethics before students have experienced clinical situations, meaning that they are unable to recognize the importance of the theme<sup>20</sup>. Moreover, the authors point out that, in most cases, the approach to these topics is considered only from an ethical angle, from the perspective of the Código de Ética Médica (CEM - Code of Medical Ethics). There is therefore the sense of a need for a greater stimulus for discussion of these issues in order to enable the construction of ideas among students and improve their personal training.

In a similar study, conducted with students in their final year of medical school, Piccini et al<sup>19</sup> also found a low level of knowledge regarding living

wills, with only 29% of respondents demonstrating a clear understanding of the subject. In this study, both professionals and students of medicine and law were analyzed, and a critical panorama of a lack of knowledge of a subject of importance to both disciplines was revealed. Such results may be partly explained however, by the fact that CFM Resolution 1.995/2012, which led to the subject of living wills being more widely discussed, was published only in the year after the study<sup>21</sup>.

Despite the large number of students who were unfamiliar with the topic, after a brief explanation of the subject, performed by researchers at time of interview, 92% said they would respect the wishes previously recorded in the living will of a patient at the end of life, against 8% who said they would make the medical decisions they deemed to be best for the patient, even if they contradicted those expressed in the document.

Such a position follows CFM Resolution 1.995/2012, which governs the subject in relation to the practice of medicine in Brazil. Article 2 of the Resolution states: *In decisions about the care and treatment of patients who are unable to communicate their will or to express their desires freely and independently, the doctor shall consider the advance healthcare directives [living will]*<sup>11</sup>. And, as stated by Gusmão<sup>6</sup>, the *CFM Resolutions, while not legally binding, are considered to be mandatory for doctors. To disobey them can be interpreted as a breach of the Code of Medical Ethics, which can cause serious problems and even revocation of the permission to practice medicine*. It is therefore imperative that medical students from this and future generations are aware of this professional duty, as well as the serious implications of non-compliance with the advance healthcare directives of terminal patients<sup>22,23</sup>.

Due to the importance given to themes of the terminal phases of illness, various religious institutions have reflected on and debated the subject. According to the *Confederação Nacional dos Bispos do Brasil* (CNBB - National Confederation of Bishops of Brazil), a doctor should accept his or her patient's desire to receive only palliative care<sup>24</sup>. In Portugal, while the Catholic Church was not initially in favor of accepting the living will, after several

debates, it now supports the legalization of this device<sup>25</sup>.

## Final considerations

It can be seen that, despite the publicity given to the theme of the terminal phase of illness by the media, many of the students interviewed were unaware of the basic concepts of the subject. Given its relevance for future doctors and for patient autonomy, the need to intensify this discussion during medical training is therefore apparent.

Most respondents had only a partial notion of the meaning of the term "living will". When asked whether they would or would not accept the patient's choice, most said they would accept. It was not verified whether this decision was influenced by religious or family issues. Other studies, which could, for example, expand the survey to other environments such as private universities or specific age groups, are required in order to answer the questions posed by this work.

The data of the present study can contribute to the ethical education of medical students and thus improve patient care, which involves the promotion of psychosocial care and support when hospitalized, conduct that also extends to the family members of a terminally ill patient. Medical schools should develop teaching and learning strategies based on the humanities, including issues of bioethics and medical ethics, in order to train doctors with a critical, ethical and reflexive vision.

The information gathered by this study may contribute to improving health services, providing guidance to healthcare managers and teams as they try to improve the care offered in terminal phase of a disease, especially with regard to the urgent need to promote discussions about the theme during training and training courses.

Finally, there is an urgent requirement to extend the discussion of the topic to wider society, informing people about the meaning and scope of advance healthcare directives, as well as making them aware of the understanding that the patient's decision should be discussed in all its complexity, and respected by health professionals.

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**Participation of the authors**

All the authors participated equally in the preparation and revision of the article. Luis Eduardo Almeida de Souza, Jorge Logan Furtado Costa and Henrique da Costa Miranda carried out data collection and wrote the original text. José Antonio Cordero da Silva coordinated the research and the preparation of the original text, and carried out a critical review.



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## Appendix 1 Questionnaire

1. Age: \_\_\_\_\_ years.

2. Gender ( ) M ( ) F

3. Year of medical course: \_\_\_\_\_

### 4. Religion

( ) Catholic

( ) Protestant

( ) Spiritualist

( ) Other: \_\_\_\_\_

### 5. When treating a patient in the final phase of life, are you in favor of:

( ) prolonging the life of a terminally ill patient through the intensive use of drugs and equipment, even while knowing that this approach could prolong and increase the patient's suffering (dysthanasia).

( ) hastening the end, adopting an active or passive approach to interrupting life (euthanasia).

( ) promoting palliative care, with the purpose of reducing suffering during the patient's final moments, without investing in treatments that aim to conserve life beyond its natural limits when there is no possibility of improvement (orthothanasia).

6. How would you define the term "living will" or what do you understand by such an expression? (Answer without

consulting any external bibliographical references, or in other words, provide your own opinion).

(At this stage, the researcher should explain the meaning of the term "living will" to the respondent).

### 7. In the event that the patient in the final phase of life has or is the owner of a "living will," would you respect the provisions of this document, subject to your own conscientious objections?

( ) Yes, I would respect the will of the patient in relation to the medical treatment that he or she wishes to receive, provided it does not conflict with the Code of Medical Ethics.

( ) No, I would take the medical decisions that I believed to be best for my patient, even if they did not coincide with his or her wishes as expressed in the living will.

### 8. During your course, have you had the opportunity to discuss the theme of a "living will"?

( ) Yes ( ) No

### 9. Are you aware of Federal Medical Council Resolution No. 1.995, dated 9 August 2012, which defined "advance healthcare directives", also known as a "living will"?

( ) Yes ( ) No

10. If you are aware of this resolution, how did you learn about it?

## Appendix 2

### Analytical framework of discourse of the collective subject (DSC)

<p><b>Clear notion of living will</b>                  Central idea – A living will is the advance expression of my will and guarantees my autonomy</p>	
<p>Key expressions:                  [1] When patients, in a lucid state, decide that they wish or do not wish to be treated in a more invasive and persistent manner in the end of life phase; [2] Documentation of the will of a patient, who while of sound mental and cognitive health, described the kind of care he or she wished to receive when in a terminal condition; [3] A document where the patient, in a condition of full autonomy, chooses policies to be followed if he or she finds himself or herself in the end of life phase and can no longer exercise such directives.</p>	<p>DSC:                  A living will is the prior expression of the will of a person by means of a written document (prepared when in full possession of said person’s mental and cognitive abilities) expressing his or her desires regarding the medical procedures to be adopted should he or she find himself or herself in the end of life phase and can no longer express his or her wishes.</p>
<p><b>Partial notion of living will</b>                  Central idea – A living will is a statement in which the patient defines the medical approach with which he is to be treated in the event of certain diseases</p>	
<p>Key-expressions:                  [1] A statement which defines the care a person is to receive in the event of suffering from a degenerative disease of the central nervous system; [2] A document in which the patient sets out his or her final requests, including with respect to how to maintain (extend) life; [3] The autonomy of the patient regarding his pathology, conduct, follow-up care; [4] The desires of a person regarding how he or she is to be treated in the terminal phase, whether treatment should continue or if the machines should be switched off.</p>	<p>DSC:                  O testamento vital é um documento no qual a pessoa relata sua vontade diante de um quadro clínico de final de vida, quando acometida por determinadas doenças: se deve ser mantida por aparelhos ou deseja que os mesmos sejam desligados.</p>
<p><b>Unaware of “living will”</b>                  Central idea – Did not have sufficient knowledge to define the term</p>	
<p>Key-expressions:                  [1] I am unaware of the term; [2] I understand it to be a written request for life to be interrupted in the event of terminal illness; [3] Current bioethics speaks a great deal about consent and information. Information is vital for the patient’s decision, which should be respected; [4] I do not recognize the expression.</p>	<p>DSC:                  I am unaware of the term “living will”, despite current bioethics discussing at length the need to inform the patient and obtain consent, respecting his or her decisions. However I understand that the term is a written request from the patient requesting his or her life to be interrupted in the event of suffering from a terminal illness.</p>