

Living will: academic and faculty knowledge at a medical school

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Abstract

This qualitative study evaluates the level of academic and faculty knowledge in a medicine program regarding the living will and its applicability, end-of-life decision making, and the concept of dignified death. Semistructured interviews were conducted with ten scholars and five professors from a university in southern Brazil. Data were obtained by discourse analysis and classified in the following categories: knowledge and applicability of living wills; view of the end-of-life process and dignified death; and the limits between the physician's duty and patient autonomy. In conclusion, this knowledge required greater dissemination to benefit patients and legally supported ethical attitudes.

Keywords: Leaving wills. Personal autonomy. Palliative care. Bioethics.

Resumo

Testamento vital: conhecimento docente e acadêmico de uma escola médica

Esta pesquisa busca avaliar o nível de conhecimento de acadêmicos e docentes do curso de medicina quanto à aplicabilidade do testamento vital, às decisões sobre finitude de vida e ao conceito de morte digna. Foi realizada pesquisa qualitativa, por meio de entrevista semiestruturada, com dez acadêmicos e cinco docentes de uma universidade do Sul do Brasil. Os dados foram obtidos por meio de análise do discurso e classificados nas seguintes categorias: conhecimento e aplicabilidade do testamento vital; visão do processo de finitude e morte digna; e o limiar entre a visão do médico e a autonomia do paciente. As conclusões reforçam a necessidade de difusão desse conhecimento para benefício do paciente e atitudes éticas amparadas legalmente por parte dos médicos.

Palavras-chave: Testamentos quanto à vida. Autonomia pessoal. Cuidados paliativos. Bioética.

Resumen

Testamento vital: conocimiento docente y académico de una escuela de medicina

Esta investigación pretende evaluar el nivel de conocimiento de los académicos y docentes de medicina con respecto a la aplicabilidad del testamento vital, a las decisiones sobre el fin de la vida y al concepto de muerte digna. La investigación cualitativa se realizó mediante entrevistas semiestructuradas con diez académicos y cinco docentes de una universidad en el Sur de Brasil. Los datos se obtuvieron del análisis del discurso y se clasificaron en las siguientes categorías: conocimiento y aplicabilidad del testamento vital; visión del proceso de fin de la vida y muerte digna; y umbral entre la visión del médico y la autonomía del paciente. Las conclusiones refuerzan la necesidad de difundir este conocimiento en beneficio del paciente y las actitudes éticas legalmente apoyadas por los médicos.

Palabras clave: Voluntad en vida. Autonomía personal. Cuidados paliativos. Bioética.

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The living will is a legal document in which patients detail the type of medical procedure they wish to undergo when their health conditions are irreversible and they are no longer able to make decisions. Advance directives (AD) include the choice of an agent to make decisions in their place, unlike the living will, which only states the patient's wishes in advance¹.

The idea of the need to obtain patient consent is of Hebrew origin and gained currency with the Enlightenment. However, it was only after the human experiments carried out during World War II that the debate on the importance of obtaining such consent led to a legal norm—with the *Nuremberg Code*, in 1947—and, later, a medical ethical norm—with the *Declaration of Helsinki*, in 1964². Originally proposed by the Euthanasia Society of America, the living will was conceived in the United States in 1967 with the aim of recording patients' wishes to interrupt life-prolonging treatment³.

In Brazil, "living will" is a kind of advance directive. According to Sánchez⁴, the latter is a general term referring to the instructions made by a person about the future medical care they will receive when they are no longer able to express their wishes. Although there is still no legislation on AD in Brazil, the Federal Council of Medicine (CFM) issued Resolution 1,805/2006⁵, which allows physicians to restrict procedures that prolong the life of patients in a terminal condition or with an incurable disease. Thus, patients will be ensured the care required to alleviate the symptoms that cause them suffering, from the perspective of comprehensive care.

Subsequently, CFM issued Resolution 1,995/2012 to regulate medical behavior regarding ADs. These documents are recognized by CFM as an expression of patient autonomy², further validating them and supporting physicians who follow their determinations.

Informed consent expresses the clearest principle of human autonomy, studied in the fields of medicine, bioethics and law⁶. In this context, knowledge on living will is necessary to ensure respect for patient autonomy and provide the best option of treatment. The document also guarantees greater security for health professionals in their practice¹.

However, no provisions were found in the Civil Code¹ to support the resolution, which raised questions about the dissemination, social acceptance and ethical principles related to living wills. Thus, knowledge on the matter must be expanded and disclosed in academia, contributing to a more comprehensive medical education. Such an effort requires assessing the knowledge of physicians and medical students about this instrument, as it aims to improve medical education and practice and ensure that patient autonomy is respected.

Method

This is a qualitative study that addresses the intensity of the phenomena and evaluates their meanings and singularities⁷ by means of semi-structured interviews with ten guiding questions about living will and AD. The participants were five medical professors from Universidade do Vale do Itajaí, Santa Catarina, Brazil, each representing one of the major areas of medicine: surgery; family and community medicine; clinical medicine; pediatrics and gynecology; and obstetrics. Ten medical interns also participated: two students in the 8th term, two in the 9th term, two in the 10th term, two in the 11th term and two in the 12th term.

The choice of medical interns enables a better assessment of students' learning level, as knowledge is acquired over the terms and thus possible differences can be inferred about living will during medical internship. The research participants were invited by the researchers through a random draw in the classes, regardless of age and gender.

The interviews lasted 20 minutes on average and were carried out individually and in person at the university. They were recorded with the consent of the interviewees for later transcription and data analysis. Following the transcription, the respondents were randomly identified as follows: Professor 1, Professor 2, Professor 3, Professor 4, Professor 5, Student 1, Student 2, Student 3, Student 4, Student 5, Student 6, Student 7, Student 8, Student 9 and Student 10. The number of participants was based on the discourse saturation method.

Data were collected between April and July 2021, followed by pre-exploration of the

interview material with the aim of gathering the main ideas and their general meanings. The data were analyzed by a set of content analysis techniques, aiming at a balance between traditional linguistics and hermeneutics. Therefore, the goal was to impartially analyze the interviewees' actual words, but also the subjective content involved in them, that is, the connotations of the semantic field⁸.

Results

Fifteen participants were interviewed, and following transcript analysis, three categories of analysis were defined: "knowledge and applicability of living wills," "view of the end-of-life process and dignified death" and "limit between patient autonomy and the view of physicians and medical students."

Knowledge and applicability of living wills

When asked about their knowledge of living will, 90% of students and 80% of professors claimed not to know it. However, when asked to define it, all participants did so adequately, as can be seen in the following statement:

"The patient can choose in advance if they want invasive measures, if they want to be intubated, surgeries and everything else. And this has to happen while in possession of his mental faculties, they can make this kind of will in advance" (Professor 2).

A living will is similar to a regular will, as it is a legal document, i.e., a statement of personal wishes designed to produce the effects intended by the agent and recognized by law. It is also unilateral, very personal, gratuitous and revocable. However, the documents differ in two essential aspects: the production of post-mortem effects and solemnity³.

Some mistaken definitions regarding living will were also observed, as can be seen in the following statement:

"(...) while alive we can donate 100% of our assets, but I know that after death it's only 50% of your assets, no more than that, that's the only thing I know" (Professor 1).

Compared to data from the study by Kulicz and collaborators⁹, 69.8% of respondents claimed not to know the concept of living will, and most participants (77.6%) reported not having had the opportunity to discuss the topic during their undergraduate studies.

This is evidence of the inadequacy of the term "living will" to designate a statement of a person's wishes about undesired future treatment. Such a statement is valid when the individual is in an end-of-life condition and unable to express his wishes. That is why a study by Penalva¹⁰ proposed that in Brazil this document be called "advance declaration of the wishes of terminally ill patients," a proposal that has been accepted by bioethicists⁴.

Still regarding the definition of living will, another misconception in the responses of some interviewees was seen: the confusion between living will and AD. This is mainly due to considering these terms as synonymous, as can be seen in these students' statements:

"For me it's the same thing, I don't know how to distinguish one from the other. I know it's a right. I believe it's a document that you write and notarize containing your instructions, in my view it's something like that" (Student 3).

"So, it's like I said, for me they are synonymous, but I could be wrong, but I've always considered them synonymous" (Student 5).

The concept of AD emerged in response to technological advances and aggressive medical treatment used in ambiguous situations, such as the case of poor prognosis. The essence of this document is the exercise of patient autonomy, protected by the AD. Therefore, when a patient loses their decision-making capacity, the document will guarantee their autonomy regarding the medical procedures to which they will be submitted, to the detriment of the decision of their legal agent¹¹.

There are two types of advance directives: living will, in which the patient specifies the medical treatments that should or should not be provided in certain situations in the future; and durable power of attorney (DPA), which consists of the authorization for the legal agent or attorney to

decide for the patient during the period in which they are not able to do so¹¹.

ADs are divided into two subgroups: statement of value and directive instruction. The former describes the patient's overall preferences and values regarding medical treatment in general, though not devoted specifically to the treatment or illness. In turn, the latter expresses the preference for or refusal of specific medical treatment in the context of a certain disease¹¹.

Regarding the applicability of living wills, 100% of the interviewees claimed never to have used nor witnessed the use of the document with any patient, as seen in the following statements:

"No, never, no, I have never used it, nor experienced it" (Student 5).

"No, so much so that I didn't even know what it was" (Student 7).

Compared to the data presented in this survey, in a study carried out by Simões and collaborators¹², the majority of the interviewees had received training on AD, 73.3% in congresses, conferences and graduate programs and 26.7% through books during their undergraduate studies. Among those people, only 16 reported having done training on medical records (30.8%); 13 did so verbally (25%); four through legal documents (7.7%); and one did otherwise (1.95%).

View of the end-of-life process and dignified death

Throughout history, death has been a founding social event for humanity, understood in each culture as a set of symbols and meanings that allows individuals to interpret their experiences and guide their actions. Mourning rituals have facilitated the integration of death, the transformation of survivors and the continuity of peoples' lives¹³.

The following precautions stand out as fundamental principles of palliative care: prevention and relief of suffering, early identification, impeccable assessment and treatment of physical, social, psychological

and spiritual symptoms. In this sense, based on the recognition of death as a natural event, palliative care advocates the active and comprehensive approach of a multidisciplinary health team, aiming to improve the quality of life of patients and their families in the face of a critical illness¹⁴.

When asked "what is your understanding of dignified death?", 46.6% of the interviewees gave statements very close to the principle of improving the quality of life of terminally ill patients, as expressed in the statement below:

"It is a process in which, as far as possible, the person understands how they got there, and if they sought help from other people, placed their body, their care, in the hands of someone else, it must be a relationship of the highest respect. The person has to feel loved, someone has to show the value of humans during this end so they can feel appreciated" (Professor 3).

Angeluci¹⁵ presents the definition of the end-of-life process, which is defined as the impossibility of reversal, either because the body does not respond to any treatments or because there is organ failure that prevents recovery.

*One must consider that, however advanced and effective biomedical progress may be, the condition of freedom from death has not yet been reached and, therefore, respecting, accepting and preparing for its arrival is also a condition for exercising human dignity*¹⁶.

According to the definition proposed by the World Health Organization (WHO), quality of life includes an individual's perception of the cultural, political and economic influences in their social context, so that their autonomy and satisfaction with life are reflected in the achievement of their personal goals¹⁴. This concern with the patient's quality of life appeared in the statement by one of the interviewees, but with reservations about a "planned" death that does not always happen:

"I think it has something to do with the way a person plans to die. An unplanned yet respected death. To respect the person's right to plan how to die" (Student 3).

Another predominant factor in the interviewees' statements is the association of death with suffering:

"(...) not having pain, trying to minimize suffering as much as possible" (Student 4).

By directly associating the word "death" with feelings of pain, suffering, separation and loss, contemporary society tends to avoid the subject, making it a taboo. Thus, healthcare professionals trained to save lives feel they have failed when patients die and keep away from terminally ill patients as a strategy to deal with this process and the feelings associated with it¹⁷.

Like birth, dying is also part of the life process, a natural phenomenon from a biological point of view. However, humans are characterized by symbolic aspects, i.e., by the meaning and values they attach to things. Therefore, the meaning of death varies over time and between different cultures¹³. For the modern Western man, death has become synonymous with failure and shame, which is why he tries to defeat it at all costs, but when he does not succeed, the fact is concealed and denied¹⁸.

Although death is everyone's inevitable fate, the duration of life and its end are different: they depend on the socioeconomic status of each individual. In Brazil, this occurs due to social inequalities structurally grounded in data such as the discrepancy in life expectancy in different regions of the country. As an example, we can mention the South and Northeast regions; the life expectancy in the former is 73.95 years and, in the latter, 68.3 years. These are regions historically marked by social and economic asymmetries that corroborate such data¹⁸.

The association of death with negative values hinders the dialogue between healthcare providers and patients in the attempt to guide them about making a living will as an individual right. Given the possibility of patients declaring their wishes regarding not being submitted to undesired treatments when they are unable to decide, not offering them the choice is configured as lack of quality care for patients. According to Siqueira Perboni, Zilli and Oliveira, *by keeping away from end-of-life patients, healthcare providers end up not offering quality*

*care to patients in one of the most delicate times of their lives. Thus, care during the end-of-life process is addressed from a dimension that is biological and technical, i.e., more objective*¹⁹.

Autonomy versus medical paternalism

In the survey, the interviewees were asked about the possibility of patients refusing the proposed treatment. The answers revolved around the arduous task of persuading them, i.e., the respondents said they should try their best to persuade the patient to undergo the treatment they believed was the most efficient, explaining their scientific reasons for this, as seen in the following sentence:

"But if it's a very serious patient who has a chance to live, I would try everything to save him, I wouldn't respect it (...)" (Professor 1).

With regard to patient autonomy, Pereira²⁰ argues that, in the case of treatment that places the patient's life in danger, there is legal permission to refuse it provided in Article 15 of the Civil Code. Thus, the question of the second hypothesis remains, in which the patient places his own life in danger by refusing the procedure. The individual's wish to refuse treatment often clashes with the State's duty to protect life, the interests of third parties and the physician's duty to provide care.

Such an analysis raises questions about the boundaries between trying to persuade patients and respecting their wishes, as their decision involves a number of ethical, moral, educational and religious aspects of their lives. Therefore, understanding their decision involves understanding the social and cultural context that led them to such a choice. Thus, in order to persuade patients to accept the benefits of the treatment offered, the healthcare provider's explanation implies knowing the circumstances in which that individual is inserted, so that this conviction is not merely based on a technical and scientific view.

That said, it must be accepted that the patients are the ones who define their health needs¹², which leads to all kinds of arbitrariness through unreasonable requests from patients, which will frustrate and also discourage health

professionals¹¹. This is present in the statement of one of the interviewees:

"(...) We understand that if you do everything by the book, things will work out, and we know well that in practice that is not how it works" (Professor 2).

A study by Pirôpo and collaborators²¹ shows that the advancement of medical technology has involved patients, family members and healthcare providers, especially when the subject is avoiding death and prolonging life and disease. According to CFM Resolution 1,995/2012²², in this context physicians are partners in decision-making regarding the patient's life and death. That makes it possible to observe the reduction of the decision-making power of physicians and family members in cases of terminally ill patients who are unable to decide for themselves.

The discussion of life and death poses several dilemmas of decisions and third-party participation that converge and diverge at the same time on end-of-life issues. Health professionals, in this context, take on an important role regarding the dignity of human life, from beginning to end. Based on the premise of always preserving life, the advent of technologies favors its maintenance and extension, a fact that has made it difficult for healthcare providers to make decisions when patients express their wish to die²¹.

In contrast to the ideology of persuasion seen in one of the 15 interviews, another interviewee stated:

"In the past I had a view that I'm trying to deconstruct, and a paternalistic view, to do everything until the end, to try and try again. Many claim that the course reduces people's empathy, but I don't think so. I think the course gives us some maturity. I don't think I'm going to try persuasion. I think it's ethical for us to always express our opinion and enter it in the medical record so as to avoid legal problems. But it's the person's life, let them live it as they wish" (Student 3).

In current medical practice, it is still common to see paternalistic behavior, i.e., when health professionals make decisions without consulting their patients' preferences, assuming that they know what is best for them. Paternalism means to constrain individual autonomy with the aim of benefiting a person whose autonomy is limited or preventing harm²³.

According to Joaquim Clotet²⁴, in the physician-patient relationship, the principles of beneficence (basic principle of medicine) and patient autonomy are complementary, so that decision-making results from joint deliberation, which is not always an easy task. It is known that respect for the principle of autonomy is not applicable to all people, since some of them cannot act autonomously because they are incapacitated or depend on an agent. Thus, this principle should have a relevant place in medical decisions and in obtaining informed consent, at the beginning of any treatment and in the assessment of acceptable risks.

Therefore, paternalism has an apparently beneficial purpose—to do what is believed to be best for patients. However, it disregards their personal preferences and cultural, social and moral background, factors that contribute to the formation of their opinions. This is strictly related to the intrinsic mindset of healthcare providers who adopt cure as the best outcome for not understanding that, in certain situations, it is only possible to relieve the patient's pain:

"There comes a time [when] medicine can no longer do anything for the patient in terms of healing, all we can do is give them comfort" (Professor 2).

Clotet²⁵ presents the following reflections: the medical principle that aims primarily at preserving the health and life of the patient (principle of beneficence), typical of the Hippocratic tradition, is being questioned. Can limits be imposed on this principle? Is it correct to predetermine medical treatment when one anticipates one's incapacity or unconsciousness? Does the state of a terminal patient imply denial and total abandonment to other people's decisions? Can the patient be the subject of the medical-hospital process that commonly precedes the end of life?

Indeed, illness is one of the main sources of perception of the human end-of-life condition, considered individually and collectively. In addition, the emergence of palliative care is accompanied by changes in the social imaginary and the transformation of the contemporary ethos, but this transformation is not without conflicts.

Although there are beliefs about the moral legitimacy of refusing "therapeutic

obstinacy”—for violating the principles of beneficence—there is no actual consensus. One of the reasons given for this refusal is the so-called “humanization” of medicine, which should also be seen as an attempt to “humanize death” or even the “dying process”²⁶.

Cano and collaborators²⁷ show that the humanization of medicine views comprehensively the patient and the biopsychosocial and spiritual aspects of the health-disease binomial. With regard to end of life, in addition to respect for people, humanized medicine defends greater interaction between healthcare team and patient, seeking better results in the choice of behaviors and treatments to promote well-being.

Life is a process that has an inevitable end, which a great many people have difficulty to understand. Subject to adversities and unaware of the end of their life, a large part of humanity has tended to deny this end, but has become hostage to life’s course. In fact, accepting the end of life is a decision with consequences that are nothing more than exercising autonomy over a supposed future condition that each one may face, in which previous choices will be able to establish the path and the responsibility of those involved²⁸.

Final considerations

The main objective of this study was to assess the level of knowledge of medical professors and students at a university in southern Brazil about living will and AD. With regard to patient autonomy, the analysis of the results shows that, although the concept of living will was partially defined by the interviewees, they had difficulty distinguishing it from the concept of AD, since most participants believe they are the same. Moreover, the applicability of living will is restricted in the

practical experience of medical professionals and none of the interviewees claimed to have used the document in any professional situation.

As for the process of end of life and dignified death, there was a prevalence of the association of death with suffering and pain. This reveals an ideology historically based on the notion of death as a symbol of loss, laden with negativism and considered a social taboo. Fortunately, all interviewees gave statements that came very close to the principle of improving the quality of life of terminally ill patients and providing comfort for their families.

Regarding autonomy, the interviewees stated that decisions about care are up to the patient, but they differed in believing that physicians should make a great effort to persuade patients of their proposed treatments. Patients’ decisions are founded on their cultural, social and emotional experiences, so the attempt to persuade them based on personal opinions or purely technical and scientific arguments goes against their autonomy.

There were also similar definitions of AD and living will among the students and professors interviewed. This raises reflections on the importance of addressing these subjects more broadly in universities that offer courses in health areas.

The dissemination of knowledge about living will still requires great advances among physicians, and their years of academic education are the most conducive period to expanding the contact of future professionals with this document. Knowing the patient’s rights and applying them is of paramount importance to guarantee their autonomy, and addressing the process of end of life and death is necessary to mitigate precepts and taboos on the subject among healthcare providers. That way those professionals will be able to offer adequate medical care to patients in the end-of-life process, with the help of knowledge of palliative medicine and bioethics.

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Lívia Angélica Grunke Cesar and Lorrayne de Aquino Solles chose the subject and did the bibliographic review, field survey, data analysis, preparation of results and discussion. Janaína Sortica Fachini helped choose the subject and supervised the bibliographic review and final version. Lauren de Matos Provim and Samantha Brandes reviewed the subject and supervised the final version.

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