

Prior declaration of will of the terminal patient: a bioethical consideration

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Abstract

The scientific and technological development brings unquestionable benefits to many spheres of human health. Therapeutic innovations and possibilities of interventions in human life processes, such as the artificial extension of life, have constantly amazed us. Therefore, we need to think carefully in order to discuss medical-therapeutic limitations, taking into account the principle of respect for autonomy, and lay down new guidelines seeking to meet the will of a terminal patient. By using the dialectic method as a guide to the investigation and analysis process, the present article sought to grasp the different perspectives to which the current discussion is subject. The approach to the statement is still poorly known, although it has lately been the main focus in the regulatory setting. This debate is expected to be able to provide inputs to the current discussion, so that new actions can be taken aiming at the key proposal of the statement itself: the guarantee of complying with a terminal patient's will.

Keywords: Bioethics. Personal autonomy. Terminally ill.

Resumo

Declaração prévia de vontade do paciente terminal: reflexão bioética

O desenvolvimento científico-tecnológico traz benefícios inquestionáveis às diversas esferas da saúde humana. Constantemente somos surpreendidos com as inovações terapêuticas e possibilidades de intervenção nos processos da vida humana, a exemplo do prolongamento artificial da vida. Destarte, necessita-se de reflexões bioéticas que objetivem debater a limitação médico-terapêutica, subsidiada pelo princípio do respeito à autonomia, de forma a fornecer mecanismos que garantam a concretização do respeito à vontade do paciente terminal. A partir do método dialético como orientador do processo de investigação e de análise, este artigo buscou apreender as diversas perspectivas a que está submetida a discussão em pauta. A abordagem em relação à declaração é pouco conhecida, embora tenha protagonizado recentemente o cenário normativo. Espera-se que este debate possa proporcionar subsídios à atual discussão, para que sejam empreendidas novas ações que visem a proposta fundamental da própria declaração: a garantia de respeito à vontade do paciente terminal.

Palavras-chave: Bioética. Autonomia pessoal. Doente terminal.

Resumen

Declaración previa de voluntad del paciente terminal: una reflexión bioética

El desarrollo científico-tecnológico trae incuestionables ventajas en las distintas esferas de la salud humana. Constantemente nos sorprenden las innovaciones terapéuticas y posibilidades de intervención en los procesos de la vida humana, a ejemplo de la prolongación artificial de la vida. De esta manera, se necesitan reflexiones bioéticas que tengan como objetivo debatir la limitación médico terapéutica, subsidiada por el principio del respeto a la autonomía, para el suministro de los mecanismos que garantizan la concreción del respeto a la voluntad del paciente terminal. A partir del método dialéctico como orientador del proceso de investigación y de análisis, el presente artículo buscó aprehender las diversas perspectivas a la que está sometida la discusión en agenda. El abordaje en relación a la declaración todavía es poco conocida, aunque haya recién protagonizado el escenario normativo. Se espera que este debate pueda proporcionar subsidios a la actual discusión, para que se emprendan nuevas acciones que objetiven la propuesta fundamental de la propia declaración: la garantía de respeto a la voluntad del paciente terminal.

Palabras clave: Bioética. Autonomía personal. Enfermo terminal.

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With technological advances applied to intensive care medicine, it was possible to provide, amongst other progresses, a notable improvement in the quality of life of patients, as well as the possibility of interference on life start and terminality processes. In that sense, we face with the possibility of an artificial prolongation of human life, which brings us to a process of “medicalization of death”.

Studies performed in recent decades indicate that over 80% of Americans die in hospitals, a rate that has grown significantly over the years¹. Nationally, it is estimated that 40% of hospital beds in the country are occupied by terminal patients². Due to these assumptions the question of what is required, optional or improper to provide the patient should be compiled. Although this posture agrees with the new goals of current medicine, it takes over the duty of taking care when the patient is in a case of irreversibility³, promoting and prioritizing his comfort in order to reduce his suffering⁴ – being the cautious exercise in the election of a proper treatment.

Leo Pessini⁵ approaches the paradigms of healing and care in healthcare, understanding that the paradigm of healing describes the use of the power of medical technology in order to extend a life artificially, regardless of its quality. Under the paradigm of care, the author continues, when medical therapy no longer achieves the goals of safeguarding health and minimizing suffering, the caregivers become obligated to avoid the use of unnecessary medications, but rather to start efforts to ease the affliction of dying.

Before the patient’s prognosis, the choice between the available therapeutic resources will depend on the purpose of each case. So, the evaluation of benefits to the patient will also have an ethical criterion to be considered⁶. According to Kipper⁴, the definition of a terminal patient refers to the irreversibility condition, by presenting a high probability of death over a relatively short time, ranging between three and six months, although the increasing and continuous scientific and technological progress has hampered the accuracy of the death prognosis.

In June 2000, the *British Medical Journal*⁷ published a study held in two London hospitals, where 74 of 76 hospitalized patients answered a questionnaire applied by an interviewer. This study aimed to determine the knowledge of elderly patients hospitalized in the United Kingdom about the living will and the desire to express their choices about health. All participants were older than 65 years old and they had normal scores on the mental test. Through a study interview, this investigation has concluded that the majority would not like to extend their

lives through the support of medical interventions when in terminal stage. On the contrary, they would prefer the health care to provide only comfort and well-being – palliative care – or, inclusively, death, in contrast to the obstinate treatments which aim the maintenance of life. Although many of the researched ones ignored or felt uncertainty regarding the possibility of taking decisions upon the prior acceptance of will or the refusing of the therapy which could extend their lives, a large percentage of those elderly people have demonstrated interest to write such term.

In a normative scenario, new considerations that lead the searching of a discussion about the medical and therapeutic limitation are necessary and based on the principle of respect for autonomy, as well as the need for new guidelines which seek to consolidate compliance with the wishes of terminally ill patients. In that sense, the present article aims a consideration on the prior declaration of will of terminal patients, based on the principle of respect for autonomy and on the medical behavior understood as orthothanasia. Those assistances are already part of the current regulatory and bioethical discussions and may befit as guides to the current discussion.

Principle of respect for autonomy

Philosophically, the term *autonomy* – from Greek *autos* (in itself) and *nomos* (law, territory) – frequently comes up associated to the concept of liberty, self-determination and the ability of the individual to take, without any coercion, decisions which will affect his life in physical, psychical and social dimensions⁸. Initially used in reference to self-government in the Greek city-states, the term started to cover up the individual aspect, becoming, over the time, multiple meanings and applications, not characterizing itself, thus, as a unique concept⁹.

The modern concept of autonomy comes from the philosophical school of Immanuel Kant. For him, the man acts according to his internal moral law. The autonomy, in the philosopher’s view, would be the ability of the human being to follow rules and values which he understands as valid, without heteronomous intervention¹⁰.

In one of his works – *Critique of pure reason*¹¹ – Kant discusses the freedom of action, defending the pure reason as a determining element of practical rules which guide the human willing. However, it is in *Critique of practical reason*¹² that he emphasizes the autonomy as a fundament of the categorical im-

perative, understanding that the autonomy of will is the element which will give sustainability to its imperative, to be followed if the individual is free to do it. For Kant, the only principle of all moral laws is the autonomy of will which presents itself in opposition to the heteronomy of will, which does not imply any obligation, but, before, it contradicts its principle and the one of the morality of will¹³. The man is free just because he has conditions to respect the will to act according to his internal moral law, his reason.

On the other hand, the British philosopher John Stuart Mill, author of a fundamental affirmation about the moral autonomy – *Over himself, over his own body and mind, the individual is sovereign*¹⁴ –, represents another ethical line of thought, the utilitarianism, and understands the autonomy as the ability to think and act of the individual, without coercion, as the right that the human being has to express different opinion regarding the one defended by the current society¹⁵. Guisán¹⁶ notes that, under Mill's utilitarian conception, the society would have the obligation of providing the means for man to reach his happiness, by realizing himself as a person and giving him the right of diverging from the State, which is not giving him the necessary conditions to this realization. In other words, for Mill, the expression of individual autonomy would be due to the right of divergent opinion. In contrast, he notes that the warranty of that liberty of opinion would be due to the social virtue of tolerance¹⁵.

It is possible to note that, while the Kantian ethics presents the application of internal moral Law as unquestionable, given by the own individual to himself, through autonomy, reflecting in his rules and values, Mill, as an utilitarian, defends that the moral rules will have value if they aim the general well-being, with the possibility of being questioned if they are not suitable. Yet both authors understand the self-determination of individuals as a right which must be respected. In this moment, it is possible to remember the thought of the British philosopher John Locke about autonomy. For him, *every man has a property in his own person* (apud Clotet J¹⁷) and he prioritizes the right to liberty of each one.

The Tuskegee study, conducted in the southeastern United States during the period of 1932 to 1972^{18,19}, led to the publication, in 1978, of the Belmont Report – Ethical Principles and Guidelines for the Protection of Human Subjects of Research, created by National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (NCPHSBRR).

This report establishes the use of principles on the approach of ethical dilemmas by following a previous proposal, authored by William Frankena, which stressed two principles, which would correspond to types of required or correct actions: beneficence and justice. In the Belmont Report, the National Commission has understood as necessary the addition of the principle of *respect to people*^{18,19}, showing concern about respect to the autonomy.

In the sequence of Belmont Report, the book *Principles of biomedical ethics* was published in 1979, authored by the philosophers Tom Beauchamp and James Childress. This work, considered as a significant advance in this area of knowledge, has established the principle of respect to autonomy, which was allied to other bioethical principles. The authors proposed a *systematic analysis of the moral principles that should apply to biomedicine*²⁰. Thus, there were established four non-absolute basic principles on the argument of acting morally in biomedicine ethics– autonomy, beneficence, non-maleficence and justice – constituting the dominant theory on bioethics for two decades.

The definition of the principle of respect to people from the Belmont Report was very criticized by Beauchamp and Childress. According to them, the report would have approached two different principles in the same reference: the principle of respect to the autonomy and the principle of protection and security to incompetent people. In this same sense, in order to eliminate an eventual dissonance, in the fourth edition of the book, there was a change on the principle of autonomy to the principle of respect to autonomy – which was considered as fundamental to the current bioethical discussions²¹.

While autonomy means self-government of the individual to take decisions on his life, integrity and health, the respect to this autonomy would be recognizing that the decision about the plan of life it is up to the individual, which is grounded in his belief, aspirations and own values, even when these ones do not coincide with the dominant ones in the society⁸.

Applying this concept to the social context, autonomy would be the way that an individual imposes himself as a person and citizen following his convictions and choices regarding his life and body, without harm to others. The respect to this autonomy would be how the democratic society provides space and protects this freedom of choice.

Autonomy of the patient

Prior to the emergence of the principlism, the respect to autonomy as an idea had already been discussed, mainly on the understanding of the individual as a subject of research and patient. On the *Nuremberg Code* itself, a document elaborated in 1947, it is possible to find such reference. So, it is important to emphasize that such document has become a historical mark on the establishment of guidelines about ethical aspects involved in the research with human beings, stating the essentiality of the voluntary consent.

On December 1, 1999, the informed consent starts to cover its competence to any biomedical human intervention, except emergency interventions, constituting itself as a human right. That advance has taken course through the *Convention of Human Rights and Biomedicine*, which was carried out in April 1997 and had the signature from 21 member countries of the Council of Europe²².

In accordance with chapter II, art. 5 of the Convention, the free and informed consent will be extended to any *intervention in the health field*²³, by safeguarding the person in question the free possibility of giving up this right. However, in a situation of emergency, as the article 8 of that chapter explains, *any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned* – therefore, it is an exception to the liberty previously demonstrated²³. Its article 9 establishes the following: *The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account*²³.

In the Universal Declaration on Bioethics and Human Rights, dated of 2005, the article 5 – Autonomy and individual responsibility – expresses that *the autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests*²⁴.

In this same sense, we can report to the recent article 101 from the current Brazilian Code of Medical Ethics, which does not allow a physician *to not obtain, from the patient or his legal representative, the term of free and informed consent for the research involving human beings, after the necessary explanations about the nature and the consequences of the research*²⁵. In its article 22, the same Code emphasizes that the physician is not allowed *to not obtain the informed con-*

*sent from the patient or his legal representative after clarifying about the procedure to be carried out, except in an evident case of death*²⁵.

Therefore, it is possible to infer that the informed consent in its practical arrangement has evolved during these years regarding the area of Bioethics and Medical Bioethics, focusing on *the overcoming of clinical paternalism inherited from Hippocrates by the primacy of the autonomy of the patient*²⁶. Clotet emphasizes this idea when he places that *the medical principle essentially aims the health and the life of the patient, known as the principle of beneficence, typical from the Hippocratic Oath, is being questioned*²⁷. And, in another work, he complements that *in the physician-patient relation, the principles of beneficence (the basic principle of Medicine) and respect to the autonomy of the patient are complementary. The decision have always to be the result of the consideration of both, which is not always an easy task*²⁸.

The increasing recognition of the autonomy and the respect to the autonomy in health consolidates positions such as from Muñoz⁸, who states that the final decision in each procedure is up to the patient, properly clarified by the health professional, and reasoned on autonomous expression of his desire. But, considering the theme – terminality of life –, Clotet questions if the patient can be the subject of the medical and hospital process which commonly precedes the end of life²⁷. The current discussions by legal instruments have defended that the consent of patients who have reduced autonomy (in the case of terminal patients) should be valued, so that these documents make the desire of this patient valuable and it prevails in future situations – an example of that is the prior declaration of desire of the terminal patient²⁹.

Orthothanasia: terminological clarification

Life and its end are constantly discussed themes, with many ethical conflicts intrinsic to this debate. Considering the technological advances, even the concept of death was modified, and in the current context it exceeds the merely biological judgment, exercising legal, psychological, spiritual and social influences³⁰.

The controversial consideration that involves death, the attitudes before it and the characterization of these conducts covers different aspects: in one perspective, there is the right to freedom of self-determination, and as a counterpoint, there is the zeal for life as an unavailable good. In this way, two great moral principles constitute this discus-

sion: the promotion of life – and health – and the relief of suffering of terminal patient. These principles, although overwhelmingly tied, raise ethical, moral and legal issues before the irreversible case of a terminal patient³¹.

When the theme regarding the terminality of life is approached, one of the most focused therapeutic conducts is euthanasia. The term euthanasia, from Greek *eu* (good) and *thánatos* (death), was used for the first time by Francis Bacon, in 1623, in his work *Historia vitae et mortis*, referring to the “proper treatment to incurable diseases”. Nevertheless, during the time this terminology has been acquiring other significations, based on more specific categorizations, thus, becoming a polissemic concept. In this way, the emergence of new terms is observed – such as orthothanasia and “dysthanasia” – which emerge with the goal of distinguishing conducts considered as ethically correct or incorrect before the process of death³². However, there are dissonances around the comprehension of these terminologies as well as around the moral evaluation of these conducts³¹. So, it becomes important to clarify the terminology referring to those several conceptual variables, and the particularities regarding the orthothanasia as a way of respect to the autonomy of the patient before death.

According to Villas-Bôas, three conducts are permissible before terminal patients: 1) to postpone the dying process under obstinate therapy and excessive use of drugs and equipment, i.e., the practice of dysthanasia; 2) to abbreviate the end of life through active or passive conducts of life interruption, which is a practice known as euthanasia; 3) to develop the use of palliative caring in order to alleviate the suffering of this patient, by giving up to mechanisms which intend to extend artificially and disproportionately the process of death, which is a measure known as orthothanasia, therefore accepting the condition of human death³³.

The orthothanasia, from Greek *orthós* (right, normal, correct) and *thánatos* (death), or *medical and therapeutic limitation* concerns in not providing or departing therapeutic resources considered as non-proportional or excessive, by reducing the use of resources which only extend the process of death when nothing else can be done to favor the cure of the patient³⁴.

It is important to clarify that the differentiation amongst orthothanasia and the other therapeutic conducts is possible by taking into account the practice of palliative caring. In orthothanasia, in the extent that it does not rush or extend the dying pro-

cess, but it provides life conditions, by alleviating all types of suffering³¹, we observe the exercise of palliative caring, which is defined as the multiprofessional practice that aims to offer the patient, outside the perspectives of cure, a service based on physical, emotional, social and spiritual aspects³⁵.

It is noted that the Brazilian *Code of Medical Ethics*, effective since April 2010, has brought essential innovations by consenting, implicitly, the orthothanasia in its chapter V, article 41, which prohibits the medical doctor to *abbreviate the life of the patient, even though it is asked by him or his legal representative. Sole Paragraph. In the cases of incurable and terminal disease, the physician must offer all the palliative caring available without undertaking diagnostic actions or useless or obstinate therapies, taking into account the desire expressed by the patient or, when he is not capable, his legal representative*²⁵.

The wording of the preexistent provisions was improved; it is as well observed the clear concern about adjusting the code to the contemporary reality of medicine exercise and clarifying eventually ambiguous concepts³⁶. Thus, this resolution becomes a significant mark before the current legal discussions regarding the medical procedure concerning terminal patients.

Normative situation

In the last years, a series of legal measures related to the theme of orthothanasia have emerged in the national context, demonstrating the currentness and relevance of the considerations proposed by this article. In Brazil, there is no specific law on the orthothanasia or the therapeutic limitation in terminal patients. However, once the Brazilian legal system accepts the refusal to medical treatment, the medical procedure is legally shielded³⁴. The right to the refusal of medical therapy is supported by the constitutional principle of dignity of the human person as it appears in the Federal Constitution of 1988.

In the State of São Paulo, there is a Law that covers the rights of terminally ill patients from the health system, allowing them to refuse medical treatment. The Law 10.245/99 states that it is a right of the patient to *refuse painful or extraordinary treatments in order to extend life*³⁷. The Resolution 41/95, from the National Council on the Rights of the Children and Adolescents (Conanda), which is bound to the Ministry of Justice, in a text elaborated by the Brazilian Society of Pediatrics, warrants the young patient or infant *the*

right to have a decent death, together with his family members, when all the available therapeutic resources have been exhausted³⁸.

In 2010, the Federal Public Ministry (MPF) deferred the Civil Public Action 2007.34.00.014809-3, which suspended the applicability of the CFM Resolution 1.805/06, which defended the practice of orthothanasia. After the review of the action and the finding of mistakes committed by the Prosecutor, MPF has started to defend the legality of the procedure. Another important factor of the national legal scenario was the Law Project that aims to regulate the limitation of medical intervention in patients whose cure is considered as impossible. This is about the LP 116/00, from the Federal Senate, authored by Senator Gerson Camata, which aims to add an exclusion of unlawfulness to the suspension of a treatment which extends the life before an irreversible case of death. This project was filed in 2003, because it was considered unconstitutional. However, in 2007, the retrieval of the proposition was proposed, and it was considered constitutional in a new judgment.

More recently, in 2012, the Federal Medicine Council (CFM), with the CFM Resolution 1.995³⁹, legitimizes the medical posture on the anticipated directives of the patients' will. Besides its currentness and innovation before the new technical and scientific challenges, it warrants, regarding the decisions on caring and treatments, the consideration of the previous and expressly manifested desire by the patient when he finds himself unable to communicate or express his desires in a free and independent way, since they are in consonance with the precepts dictated by the Brazilian *Code of Medical Ethics* – and this desire shall prevail over any other non-medical opinion, including on the desires of the family members.

In another article of the resolution, it is written that, when the patient has designated a representative for this purpose, their information should be taken into account by the physician. Still according to the resolution, the physician must register the anticipated directives of willing directly communicated by the patient on the chart.

Prior declaration of will of the terminally ill patient

The prior declaration of will of the terminally ill patient, most known as living will, has emerged as a legal document in California in the 1970s⁴⁰. The living will determines the right of the patient to consent or not to submit himself to medical therapies

when he can no longer express his desire at the decision-making moment, being in incurable or terminal conditions. Such understanding agrees with the concept defined by the CFM, according to the Resolution 1.995/12, for anticipated directives of will of the patient, with these considered as *the group of desires previously and expressly manifested by the patient on caring and treatments which he wants or not to receive when he is unable to freely and autonomously express his desire*³⁹.

According to Penalva⁴¹, in Brazil, the expression “*testamento vital*” was used as a reference to what is understood as prior declaration of will of the terminally ill patient, as a result of successive and mistaken translations of the North-American expression *living will*, based on the possible translations of *will*, which, according to the Oxford dictionary, could represent “wish”, “desire”, “testament”, as well as *living* could import the idea of “support” or “alive”, “living”. There is no consensus regarding the synonymy of the terms: if, in fact, there was a mistaken translation or if the goal would be to equate the idea of the document to a testament. About this last hypothesis there are some divergences, due to the nature of *post mortem* effectiveness of a testament providing acts of will of an individual.

Before the referred discussion, a new terminology has been proposed, which is more reliable to the proposal of the original term, intending to suppress any non-conformity. Some previous proposals were considered, for instance the terminology “prior instructions”, used in Spain, as well as the “declaration of will of the terminally ill patient”, but they were resigned due to not complying with the idealization of the situation which they had been proposed. Finally, grounded in the idea of a declaration of a will to be employed by the patient in a situation of terminality, but that should be previously expressed, the current term was found – prior declaration of will of terminally ill patient⁴¹.

The first approach about the prior declaration of will of the terminally ill patient, referred under the original expression *living will*, was proposed in 1967 by the Euthanasia Society of America and characterized as *a document of anticipated caring through which the individual could register his desire of interrupting the medical interventions of life maintenance*⁴². In 1969, in Chicago, Louis Kutner, at the time he was a lawyer, created the first living will, fighting for the right of the terminal ill patients to have their desires safeguarded regarding the treatments of life supporting – it is curious to observe

that his inspiration was attributed to a friend who was suffering of a painful illness⁴³.

The case of Karen Ann Quinlan was the first one reported to the American Courts, in 1975, in the State of New Jersey. Her adoptive parents, when they were informed about the irreversibility of the state which their daughter in coma was encountered, requested the withdrawing of the respirator which had been maintaining her life. After some medical refusals, which were motivated by moral and professional reasons, the parents asked the Judiciary Power of the State, searching for authorization for the interruption of the therapeutic effort, reasoned on the anticipated manifestation of their daughter, who would not like to have her life maintained by apparatus.

The request was rejected in first instance, considering the absence of legal support, being referred to the Supreme Court of New Jersey, which delegated the assessment and prognostic of the patient to the Committee of Ethics of that hospital – which had to be created, since it was inexistent. After the conclusion of the irreversibility of the clinical state of Karen was encountered, in March 31 of the following year, the Court authorized the interruption of the therapeutic effort. However, the patient was alive for nine more years with the same clinical picture, even though without the apparatus aid⁴⁴.

In the following year, 1976, the California State approved the document entitled Natural Death Act, elaborated by the Law School from the Yale University, which has become the first legal diploma to authenticate, in fact, in a textual form, the anticipated guideline of will of the terminally ill patient. In California, another document, the Guidelines and Directive, was elaborated by medical associations with the aim of helping physicians on the use of artificial methods of *extending life*⁴². Other American States have regulated the living will, in consideration of the approving of the Natural Death Act.

The case of Nancy Cruzan, which reached a great national repercussion, has been characterized as a decisive factor on what would become an American Federal Law, being taken to the Supreme Court in 1990⁴². After a car accident, in 1983, Nancy's parents requested the withdrawing of the apparatus that were keeping her alive, since the diagnosis was of permanent and irreversible coma and according to the anticipated desire of their daughter⁴⁵. With the denial in the first instance, the case reached the American Supreme Court, which deferred the request in 1990, ordering compliance with the desire of the patient.

In front of the established public outcry, increasing the discussions around the theme, in 1990 the Patient Self-Determination Act (PSDA) was approved, instituting the first American Federal Law to recognize the right to the self-determination of the patient⁴². The project authored by senators J. C. Danforth and D. P. Moynihan became PSDA Law, approved in 1990 by the United States Congress and effective since December 1, 1991²⁷. Clotet clarifies: the PSDA recognizes the right of people to take decisions on health caring, there included the rights of acceptance and refusal of treatment, and of written register, by document, of the same options, predicting an eventual and future inability for the free exercise of the own will²⁷.

Once each state in the USA has autonomy to legislate regarding specific subjects, PSDA is much more characterized as a guiding policy⁴². As Penalva says⁴², about 35 U.S. states have their own laws on this anticipated guideline of will.

Also in the international scenario, Portugal has been highlighted because of the discussion on the legalization process of the living will. In 2006, the Portuguese Association of Bioethics forwarded a law proposal on anticipated guidelines of will to the Republic Assembly, promoting a wide-ranging debate. In 2009, the Socialist Party presented the Law Project 788/X/4^a on the Rights of Patients to Information and the Informed Consent⁴⁶. Such project was integrally approved by the Assembly, but it was rejected by the National Council on Ethics for Sciences of Life (CNECV). In 2010, another document about living will was sent to the president of the Assembly, whose audition was carried out in March from that year. During the audition, the rapporteur of the association defended that the model of living will should be done by the regulator entity of health, which is also responsible for the supervision that the will of patients is being accomplished⁴⁷.

In the same year, the other documents (law projects 413/XI⁴⁸, 414/XI⁴⁹, 428/XI⁵⁰ and 429/XI⁵¹), which jointly approached an informed consent, the right to information and living will, were proposed by different political parties. At the request of the Parliamentary Commission of Health, CNECV issued a memorandum in December 2010⁵², which has served as basis to the Opinion 59⁵³ from the same body about the projects of law regarding the anticipated declaration of will. This opinion addresses to two dimensions: the necessity of the national law to clarify the possibility of revocation, even verbally, pursuant to the anticipated declaration of will by the individual himself and the designation of the

attorney on health care⁵³. However, these projects expired in 2011⁵⁴.

In 2012, Portugal published the Law 25, which regulates the anticipated guidelines of will, under the form of living will, and the appointment of an attorney on health care, and created the National Register of Living Will⁵⁵.

For Stancioli²², the new model of the physician-patient relation requires from the professional not only a technical acting, but also social one. Regarding the technical acting, the health professional is responsible for the diagnosis and the selection of therapeutic strategies; under the social prism he is also responsible for the dialog with the patient, searching for his effective consent. The human dignity lies on the idea of unrestricted respect to the human being and, contrary to the expressed will of the patient, submitting him to a determined treatment may characterize private prison, illegal embarrassment and even bodily injury⁵⁶.

Even considering the raising acceptance of the idea of respecting the anticipated manifested will of the terminal patient, questions regarding the patients competence arise on the decision-making in front of the terminality of life, since he is weakened by the disease. In that sense, the living will, as an anticipated guideline, has been defended as a legal instrument which aims to register the expression of his desire to prevail in future situations, indicting contestations regarding the valuation of consent spoken by this patient²⁹. In this sphere arises the need for consideration in relation to the process that precedes the end of life, considering that (...) *there is an intimate untransferable dignity (...) according to the subject's own self-assessment*⁵⁷. Therefore, thinking of the dying process, and not only of death as an event or occasion, it would be a way of warranting the validation of our choices and designs.

With the legalization of PSDA, the modality of anticipated directive, known as long-term mandate, emerges⁴¹, and characterizes itself as a specific mandate with powers to an attorney or nominee, who is responsible for the decision making when the patient is terminally ill and incapable – supplying his will and attending his supposed designs²². It is worth to observe that the applicability of the long-term mandate is not restricted simply to situations of life terminality.

Regarding the orthothanasia, the prior declaration of will of the terminally ill patient as a testamentary provision would guarantee the patient the avoidance of the practice of an obstinate therapy, known as dysthanasia, in which he is submitted to a

painful and suffering death process. In this way, such document, since the necessary conditions are fulfilled, presents legal value and includes the civil and penal prerogative of the physician who acts in accordance to it. To the physicians that do not agree with such decision, due to moral and professional reasons, it remains the duty of referring the patient to the health care of another physician or institution²².

Given these statements, the prior declaration of will of the terminally ill patient has the purpose of warranting the respect to the decision of the terminal patient, as well as, and not least, to provide legal support to the medical conduct before those conflicting situations (Lepargneur H. *apud* Pessini L, Barchifontaine CP⁵⁸).

Corroborating with such statement, an article depicting the view regarding the humanization in the final phase of life was recently published⁵⁹. In this work, an applied research was performed to physicians whose activities involve terminal patients. The presented results indicate that, regarding the position of the physicians, 90% of the interviewees adopt the emotional support with their patients and 70% state that they talk about the illness. However, 80% prefer not to clarify the estimated lifetime. Although 100% of the interviewees agree that the palliative care increases the quality of life of the patient in terminal stage, only 50% state that they adopt this type of care with them.

Another important discovery reports that, when asked about which improvements were observed in the patients with the adoption of palliative care, 70% of the participants have observed the relief of pain, 60% have observed the improvement of self-esteem and 50% have verified improvement of depression and acceptance of the state⁵⁹. Besides the great innovation and contribution of this investigation, it was verified that the position of the physicians regarding the palliative care is still fragmented, presenting difficulties referred to the terminality of life, especially regarding the clarifications and the options of the patients, reporting the necessity of expansion of the related discussions.

Nationally, there is no legislation referring to the validation of this anticipated directive. Diniz⁶⁰ presents a model of document called Anticipated Guidelines Regarding Health Treatments and Attorney Granting, which is similar to the proposal presented by the prior declaration of will of the terminally ill patient, guarantying the right of therapeutic refusal from the patient independently of the contrary position of his family members. According to some researchers, an alternative to

the living will would be based on the cited free and informed consent, which is consecrated as a competence for any human biomedical intervention and that has featured the discussion of organ transplantations⁶⁰.

Despite the right to refuse to ineffective medical treatment exists independently of specific law about the theme, it is stressed that the Resolution 1.995/12³⁹ provides the possibility of the terminal patient to decide about the care and treatment he wants or not to be submitted in the case of a probable inability of freely exercising his desire. However, there is still a need for legal provision regarding the formal requirements of this declaration of will.

Many authors suggest substantiating this discussion from the example of foreign experiences. Several topics are still not established, such as the necessity of a normative and specific law, the provisions which should be inserted in the declaration, their validity, and the creation of an exclusive national bank, among others⁴². Some researchers, such as Penalva⁴¹, raise these questions and have carried out important studies in this sense, suggesting certain directions which are supported on the experience of other countries' aim to warranty the legal security and greater effectiveness to fulfill the will of the terminal patient on normative discussions in the Brazilian legal context.

Final considerations

The unquestionable technical and scientific advance of medicine has brought an increase in human life expectancy – which doubled in the period from 1800 to 1960. We are constantly “bombarded” by therapeutic innovations and several possibilities of intervention in the processes of human life. In the social view, *medicine has replaced religion and physicians have become the new priests of salvation in a technical society* (Byk C. *apud* Junges JR,

Cremonese C, Oliveira EA, Souza LL, Backes V⁶¹). In fact, the physician-patient relation has acquired new approaches. Although they are non-absolute principles, the principle of respect to the autonomy and the domain of man on his body and mind have gained strong ethical and moral foundations, and its practice in intensive care medicine has had remarkable evolution over the last few years. The principle of beneficence, typical from the Hippocratic tradition is being questioned²⁷ and the patient starts to get involved in the process of decision-making, by making his manifested will prevail.

In front of this imminent possibility of interfering in the processes of human life, among them the extending of the dying process (even though under obstinate therapeutic procedures), the meaning of death and the understanding of finitude started to integrate this discussion, expressed by the idea of decent death. In this sphere a new question about the free choice of the person before death is opened⁶² and if it would be possible for the patient to be the subject of the medical and hospital process which precedes the end of life²⁷. Nowadays, a resolution of CFM provides the respect to the autonomy of the patient, one of the basic principles of the bioethical principlism, but there are still discussions regarding the way this declaration is produced, which aims to institute the patients right to refuse to submit himself to disproportional therapies even at the moment when he could no longer express himself.

In fact, there are still moral issues to be discussed around the institution of this declaration, whose approach is little known. While we have seen great advances in the normative area, legal clarifications are still necessary, being needed new contributions from professionals of several areas related to the theme, promoting, thus, the dialog among them. It is expected that this consideration provides subsidies for the implementation of actions which aim the fundamental proposal of the own declaration: the warranty of respect to the will of the terminal patient.

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Authors' participation

Andréia Ribeiro da Rocha, Giovana Palmieri Buonicore and Anelise Crippa Silva worked in the conception, elaboration and listing of the pertinent bibliography. Lívia Haygert Pithan and Anamaria Gonçalves dos Santos Feijó worked in the conception, guidance and final revision.

