

Legal and ethical reflections on end of life: a discussion on orthothanasia

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Abstract

Legal and ethical reflections about end of life: a discussion about orthothanasia

The article aims to present ethical and legal bases for orthothanasia. The search for knowledge bases on data available online and on printed literature with the relevance of articles for the discussion of orthothanasia as inclusion criteria. The practice of orthothanasia is discussed both in medical and in bioethical terms. The article presents the difficult situation of patients, family, and professionals in a delicate and doubtful moment, when the end of life is near. Law, ethics, and criteria of dignity regarding the practice of orthothanasia are discussed. The article has reflections about death, ethical dilemmas, and actions of professionals in context of terminal patients. Prolonging patient's life yields very complex situations, but the limit of investing in life must be defined by the vision of decent death, with a full conscience of the limits of interventions. The best solution to each situation is directly connected with the dignity of the person who suffers the inevitable process of death, respected his decision.

Key words: Death. Hospice care. Bioethics. Orthothanasia. Right to die. Medical uselessness. Passive euthanasia



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Ancient Greece believed that physicians had the healing power delegated by gods. Therefore, they became semi-gods in a rigidly defined social relations society of citizens and non-citizens (slaves and foreigners). What physicians prescribed had to be complied without questioning.

Descartes underlied scientific method, centuries later, in sound rational bases leaving aside gods and started to divinize medical science itself. Technology becomes capable to undertake anything: prolonging life, increase people's well-being and, why not, avoiding death¹. The end of life becomes a non-admissible accident, and all means have to be used to, at least, delay it.



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Out of this difficulty in accepting death arouse the discussion over the stalemate between artificial methods to prolong life and the attitude of letting disease to follow its natural history. Euthanasia, disthanasia, and orthothanasia are the focus of this discussion worldwide. Euthanasia is illegal in Brazil but accepted in other countries, which do not consider it as aggression to Law and moral. Disthanasia is the unmeasured investment that tries to extend life at any cost. Finally, orthothanasia identifies with medical attitude of accompanying the moribund to a painless death without using disproportional methods to extend life, such as ventilation or other invasive.

The publication of Resolution no. 1,805/06 by the Federal Council of Medicine (CFM)², about orthothanasia was an important step that introduced the topic in the health professionals' agenda, reason for debate on its ethical and legal features. The fact that the Federal Public Attorney's Office (MPF) suspended it, it became even more important and necessary to discuss this important topic of health professionals' daily practice.

Recently, the New Medical Ethical Code entered in force, approved by CFM Resolution no. 1,931/09, published in the Official Gazette of 9.24. 2009, and rectified in 10.13.2009. This new Code, publicly discussed during two years, incorporated not only suggestion by the medical sector, but from the entire civil society and it deals with discussions on terminal patients' care and the extension of useless life or dogged with palliative clinic situations. Such fact, although important to incorporate the idea of terminal, still lacks unison understanding in society, reason why this code enter in the scenario of current discussions.

Despite the issue is full of uneasiness, the legal and ethical basis is in constant analysis by the world scientific community.

Patient's personal earnings and conceptions as well as that of his family, who jointly live this final instance of life, must be discussed broadly, since only then practiced acts will be closer to what is fair and dignified for the patient in terminal stage of life.

The objective of this study is to present ethical, scientific, and legal bases in face of orthothanasia and the dilemmas of end of life, particularly in the bioethical view of dignity and human rights.

Method

A survey was undertaken in major online database as well as in printed literature. The criteria for Inclusion of articles were the relevance for discussion of orthothanasia, bearing in mind the following topics: differentiated characterization of concept, ethical reflections and legal basis for its use, the clinical practice at the end of life.

Orthothanasia: concept and ethical reflections

The differences between disthanasia, euthanasia, and orthothanasia practices are ignored, often, making it difficult to form a sound opinion, turning the professional incapable to react and to decide in face of determined situation.

Etymologically, orthothanasia means correct death – *orto*: right; *thanatos*: death. It means not prolonging artificially the death process beyond what would be the natural process.

This practice is known as the manifestation of the good or desirable death, not occurring extension of life by means that would imply in increase of suffering³.

Disthanasia is in counter position to orthothanasia as it aims to extend life at any cost, even with patient's suffering. It is a much arguable practice, since it extends patients' agony without expectation of healing or improvement in their quality of life.

Euthanasia, the death process of a diseased through intervention aiming ultimately leading to death, alleviating an unbearable suffering, is the most well known practice. Its punishment will depend on the country where it takes place. In Holland, it is not considered a crime. Greece, Poland, Austria, and Norway have light penalties. Its practice is not considered a murder in Germany, Italy, and Switzerland and, by law, it must be judged as special case. However, in France and Turkey its practice is considered as murder^{4,5}.

Reflection about the legality or not of the three practices is the target of intense discussion in several countries. These reflections and discussions bring along candescent questions, such as the right of a dignified death when it is unavoidable, although it cannot be confused with what it is called the right to die³. Opposition lies between the power of taking life when there is possibility of living or to extend agony, with suffering and pain, when there is not this possibility any longer.

What is the choice power of the patient or of his family when he is in a terminal condition where there is not any hope for healing or recovery? Should his autonomy to choose, or that of his closest people, be taken in consideration or totally ignored by professional treating him?

Just as life, a dignified death, without pain or anguish, is a human right. Autonomy and dignity at the end of life may offer solutions and paths in order to respect this right⁶.

There is the necessity to respect the freedom of choice for diseased, taking in consideration his competence to decide, autonomously, on what he considers important for his own life, including the dying process, in accordance to his values and legitimate interests⁷.

The complexity of discussion transcends the pure act of understanding concepts, involving a reflection on action and consequences of this practice. The struggles for life or the induced death or relief of pain are situations that provide much difficult discussions, which can be interpreted in different ways. Therefore, they need spaces in order to be judged and reflected, in search of an individualized and ethical good.

Legal bases and historical comments

The proposal for reforming the Brazilian Penal Code, in 1984, foresaw the express inclusion of orthothanasia

as non punishable, in Art. 121, paragraph 4, but this change was not approved. The bill stated that orthothanasia is cause for exclusion of illicitness of homicide not constituting crime to stop keeping someone's life, if previously certified, by two physicians, of the eminent and unavoidable death, and as long as there is consent or in its impossibility, of ascendant, descendent, spouse or brother¹.

One should note that the text referred to orthothanasia and not to euthanasia. Paragraph 3 foresaw the situation in which death process had started already with life kept artificially without chance of healing or improvement. There is only the extension of the natural death process in this situation. It is not the foreseeing euthanasia where such process did not start yet, although patient suffers incurable disease. Euthanasia produces the immediate cause of death, which is crime, fitting in the provision of privileged homicide in the text of current Penal Code.

CFM published in November 28, 2006 Resolution no. 1,805/06 based in Article 1, item III, of the Federal Constitution, which has the principle of human dignity as one of the foundations of the Federative Republic of Brazil. It yields a conception that allowed CFM to resolve *at the terminal stage of severe and incurable diseases, it is allowed to physicians to limit or suspend procedures and treatments that extend the diseased life, ensuring him the necessary care to relief symptoms that lead to suffering, within an integral assistance, respected patient's will or of*

his legal representative ².

In the following year, attending an injunction request by the Federal Public Attorney's Office in the Federal District (MPF/DF), the effects of CFM Resolution no.1,805/06 were suspended. The judge adduced that, in superficial analysis about the request, despite the Federal Council of Medicine presenting justification in the procedures that orthothanasia does not anticipate the moment of death, only allowing death in its natural course, this situation does not deviate the circumstance that such behavior *seems to characterize the crime of homicide*. He reiterated that, according to the Penal Code, Article 121 always encompassed and it seems to encompass both euthanasia and orthothanasia

Abstracting the good intentions and fair objectives of the resolution, it has serious practical and bioethical implications. For example, the risk for patients interned in public hospital be compelled to accept the procedure in order to cede scarce vacancies to other people with chance of healing, or the risk of typical fallibility of any diagnosis, existing always the chance, although remote, that a new technique may cure the patient.

During the plenary session of the Federal Council of Medicine, 4.12.2010, it was consolidated the application of the Medical Ethical Code (CEM) starting in 4.13.2010, which was approved by CFM Resolution no. 1,931/09, published in the Official Gazette in 10.13.2009. The new CEM comprises a foreword

with 6 items, 25 fundamental principle items, 10 items on rights, 118 Articles on deontological norms (about duties) and 4 items about generalities. That is, the scheme of principles, rights, and duties was kept. Within the scope of discussion hereto, CEM now counts with Article 41, which explicitly states: *It is prohibited to physicians to abbreviate patient's life, even at his request or of his legal representative*. It is followed by a single paragraph that states: *In cases of incurable and terminal disease, physicians should offer all available palliative care without undertaking useless and dogged diagnosis or therapeutical actions, always considering patient's expressed will or, in his impossibility, of his legal representative*. The code presents still, in its fundamental principles, the parameters for medical performance in terminal cases, as in Chapter I, item XXIII, in which it quotes: *In irreversible and terminal clinical situations, physicians shall avoid undertaking unnecessary diagnosis and therapeutical procedures, and he shall provide patient under his care, all appropriated palliative care*.

Thus, discussion on terminal cases so present in medical practice, independently of philosophical conceptions, was contemplated not only in disciplinary document for the physician or as well as determined just by the medical profession. CEM is subordinated to the Constitution and law, and once discussed with the community, approved, and broadly disseminated, it contributes toward consolidation of patient's rights to care, in needed quantity and quality for the

moment he lives, including the end of his life.

Distinction between dying with dignity and the right to die

In the context of present discussion, it is very important to bear in mind the distinction between the right of a dignified death and the right of decision about death. The right of a dignified death relates to the desire for a natural death, humane, without extending life and suffering by means of useless treatment. However, the right to die is synonym to euthanasia or a help in committing suicide, are interventions that cause death.

It is necessary in order to consider and to conceptualize what is a dignified death, *a priori*, to conceptualize what is a dignified life. This should be analyzed from health standpoint, understood as quality of live or biopsychosocial wellbeing of the human being, inserted in his historical, socio-cultural, and environmental context, enabling full development of the individual. Any attitude that may hurt this quality of life is disrespect for the dignity of the human being, a fundament of the Brazilian State. In this context, dignified death relates to the dignity of the human being, basis of bioethical and medical ethics principles, and presumption of higher value that must be respected in the clinical practice. Dignified death emphasizes respect for the dignity of the infirm, not keeping him artificially connected to devices, piped with assisted breathing, and with artificial maintenance of vital signs, without any possibility of healing, and in an initiated

death process. It has to do with non-aggression to human being dignity, his right to autonomy (whenever possible) in deciding about suspension in using disproportional means. Patient's dignified death may occur in a hospital or residential environment, always in presence of beloved ones, relative and people of his companionship, supported by qualified medical team with palliative care, as stated by Lu s Gonzaga do Amaral, councilor at the Regional Council of Medicine in the State of Minas Gerais (CRM-MG) to the newspaper of that institution.

The 1988 Federal Constitution ensures in its Article 5 the inviolability of the right to life, freedom and safety, but it does not set the duty of life and freedom. The right (not the duty) to life does not foresee that patient must be submitted to useless treatment when there are not possibility of recovery. The patient's right of not submitting himself to treatment or to interrupt it is consequence of the constitutional guarantee of his freedom, legal autonomy, inviolability of his private life and intimacy and, mostly, the human dignity erected in Article 1 of the Federal Constitution. Item XXXV of Article 5 assures, inclusively, the patient's right to go to Court to prevent any illicit intervention in his body against his will. Inviolability to safety involves inviolability of physical and mental integrity.

According to Maria Celeste Cordeiro dos Santos, assistance to death is *licit whenever it occurs without shortening of life*⁹.

Author names orthothanasia of *medical assistance to death*, understanding that *physician (and only him) is not obliged to interfere in extending patient's life beyond its natural period, except if expressly required by the sick individual*¹⁰.

Currently, while still in force the Federal Public Attorney's injunction which suspended CFM Resolution no. 1,805/06, it upholds the support to procedure related to a terminal patient, corroborated by the new Medical Ethics Code.

Health professionals and orthothanasia

Bioethics deals with issues related to the beginning and end of life. These instances were considered as natural phenomena until mid 20th century. Today, on the opposite, they are more artificial, making decisions about interventions very complex, such as, for instance, the definition of death for organs donation¹¹.

Nevertheless, medicine lives a moment of search for balance in patient-physician relationship in face of the fast incorporation of technological advances: **intensive care units (ICU)** and new methodologies that allow to evaluate and to control vital variables, offering to professionals the possibility of extending the moment of death. The technological arsenal available currently is such that it is not unfit to say that it is almost impossible to die without physician's agreement. **There was a significant increase in the intervention power of the physician,** without need reflection

over the impact of this new reality on the infirm's quality of life, where physician's classical function – *to heal, sometimes; to relieve most often and to comfort, always*– is set aside, as one relegates the care for the sick person, and one emphasizes the treatment of the disease. Thus, the obsession for keeping biological life at any cost leads to therapeutical obstinacy and disthanasic situations¹².

The increase in life expectancy and survival of individual suffering diseases, thanks to the development of medicine and technology resources, raises several bioethical questions, introducing punctuations in humanizing interpersonal relationships and care, and rousing discussion on the legitimacy of the human and economic cost of a disproportional extension of life. In this context, health professionals need greater understanding about care with life and the dimensions of death, of dying, of pain, and of suffering¹³. Therapeutical and diagnosis resources progress modified the profile of death, previously due to infectious diseases, considered as lethal, to non-transmissible diseases, susceptible to treatment and interventions that significantly extend patients' lives.

The issue of humanization of pain and human suffering in health sector bring, beyond physiological features, reflections on the loss of human integrity and consequent loss of quality of life. Therefore, it is necessary to pay attention to the trend of clinic to concentrate treatment just on the physical symptoms, as if these

were the sole reason for patient's torment¹⁴. Therefore, one reduces treatment to the possibilities of interventions from the technological arsenal, without due simultaneous investment in human dignity, here represented by the act of caring.

Humanized care and guarantee of human dignity at the end of life became issues of first order for medicine and present society in face of bioethical challenges of extending life and with technological and therapeutical support progress¹⁵.

However, the progressive and accelerated increases of medical specializations encompass problems of epistemological-didactic order and, above all, ethical. This happens due to volatilization of the holistic and historical conception of the patient and, more precisely, due to the diagnosis fragmentation and non-personalization of the disease. Configuring a *scientific reductionism*¹⁶, this fragmentation of medical knowledge caused by the arising of innumerable specializations increases the possibilities of getting data about pathology, diagnosis, and treatment, but it makes difficult the competence of professionals do visualize the bearer of a disease as a subject, and to capture the human complexity of patient-physician relationship.

It is indispensable for the health professional to overcome the inherent difficulties of patient-physician relationship based on the *technological temptation*, visualizing patient as a whole and, thus, establishing a commitment with full life in as much as higher good worthy of respect. It is necessary, also, to avoid adopting a mechanical posture, dissociated of the most intrinsic human aspects, and to enlarge

the focus of attention, while caretaker, without losing sight of comprehension of the individual who gets sick in his singularity and dignity¹³. It means the *imperious need of solidarian care that links technical-scientific competence and humanity, mainly in extreme situations at the borderline between life and death*¹⁷. To that end, it is indispensable to train professionals, at the academia, imbued of ethical values and respect for human dignity, qualified and skilled to assist and to care subjects in critical situations of life and death.

Currently, health actions are marked by the healing paradigm, whose focus is in the interventions in the disease and not in the individual, sustaining idolatry for the physical life, trying to postpone death, taken as a fault of modern medicine¹⁷. Here, conflicts experienced by health professionals in face of bioethical issues and own values set a correlation of forces that stresses this realm. The death process of the subject, under this topic, configures as a kind of death at its *correct time* (orthothanasia), without *disproportional treatments* (disthanasia), and without the intervening occurrence of abbreviation of the dying process (euthanasia).

Among the basic principles of the palliative care is the conception that death is a natural process and consequent suitable caring practice in the context of orthothanasia, which implies in not causing euthanasia nor inducing disthanasia of patients in their last days of living¹⁸. Thus, the orthothanasia advocates *dying with dignity*.

However, exacerbating still the issue on life and death, it should be brought Shakespeare's reflection when he describes the most inexorable of our existence, that is, death. "*Nothing else. This is the end that we should request anxiously. Dying is to sleep, sleep....perhaps to dream...*"¹⁹

Therefore, it is necessary a greater reflection about the beginning and the end of life, a process that all are submitted, and that should occur in the most humanized possible way, directed by the deepest ethical principles.

Ethical considerations about the beginning and the end of life

One could think the beginning and the end of life in a simplified and materialist way, inclusively positivist, with *strict* limit in medical language. A gynecologist would say that life starts at the moment that occurs the nesting of the conception products on the wall of the endometrium; thus, it could also be said that its end is the moment when brain activities cease.

Nevertheless, this definition about the beginning of life is too technical, expressing only the need to find a concrete and tangible instance. Actually, it could be conceived in previous instances to birth process, depending on the advocated standpoint and of personal conceptions. Despite the gynecologist thinks that life starts at a specific instance, it is the outcome of a complex and continuous process.

Despite the complications inherent to the definition of precise instance of the beginning of life, the end is viewed,

generally, as something concrete, defined and not passable to doubts. However, it seems simplicity to define death just in technical terms. There is no doubt that it is also a complex process, with deep biological, psychological, and emotional changes prior to the event itself. Except for individuals with a sudden death, those presenting diseases with progressive picture, limited diagnosis, and known natural history, these general changes are very touchable.

Death, understood in this complexity, stops being just a passage and becomes an instance of deep changes, rich in emotions and necessities for those who are close to it. The universe of feelings, the complexity of limits of living and dying become the object of frustrations and of thought in the imaginary of these people, being, therefore, of extreme importance for health professionals to know how to deal with such situations. Based in this reality, someone close to death may think that his life *does not need to be lived anymore*, since he is far from what he thought to be *his living*, equally for someone deprived of his physical capability, living with the support of devices, may think that his life is over. In these cases, the limit between *feeling alive* and *being alive* is complex by nature. According to Canguilhem²⁰, to *be sick is to live a different life* – but, when the individual decides that he does not want to live anymore, due to unbearable difference of what he conceives as life, how should the health professional react? Certainly, the answer is not easy, but rather personal, and it must be duly discussed and analyzed.

Recent decisions in the United States and Europe are favorable to patients having unlimited rights to refuse any treatment. Exception exists only in cases when individuals are not capable to take such decision, which is delegated to family. There is significant doubt in discussions about the final period of life: what is seriousness of the neurological conditions of a patient and the respective forecast in order to allow thinking in withdrawing the support to life?

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Analysis of cases is particularly difficult in face of the existence of feeling not only of the individual but of his family as well. Medicine only goes to a certain limit, and the therapeutical procedures are absolutely finite, and the question of when they start to be useless is set. The word seems heavy, but actually is a reading of the situation in which nothing helps the individual, but rather it tends to extend something that needs to be well decided with the most interested person: the patient – who may be included actively in the decision-making on the highest good: his dignity. It has to do with the desire of living within one's capability, of deciding that perhaps it is not desirable to live with what is therapeutically available.

The average life expectancy doubled from 1800 to 1960 with the potentialities of medicine in struggling against illnesses. Socially, medicine replaced religion, and physicians became the new salvation priests in a technical society²². Power that makes them, and the other health professionals, anguished because at the positivist origin of the medical thought is to diagnosis and to

cure. The possibility of death leaves the professional without suitable answer for the situation, since decision become just technical and based in protocols, as if life could be measured in averages and deviations.

Pathology, for Canguilhem, may be a normative variation of life, not directed by the same norm as physiology, that is, it relates with life and not with health²⁰. The sick person has the capability to modify his pathological status to the point of adapting himself to this new situation, becoming capable to live with it in a state of normality. The problem occurs when the individual does not have the power anymore to modify and to adapt, losing what exists in him of autopoiesis, and generating a pathology. If this is serious and terminal, his capability to live is reduced to an *almost nothing*, felt as lack of minimum dignity, leading him to consider the option of abbreviating his own life.

Valuation of what is experienced by these people may and should help health professionals to listen, accept, and to have empathy with what patients feel and live in critical moments of life. This is not an easy task, but necessary so decision-making respects patient's dignity.

In recent qualitative study, undertaken by general practitioners, it was evidenced that almost half (14/30) avoided euthanasia and assisted suicide because it was against their own values and it was painful to face these issues. The study showed also that general practitioners did not feel comfortable with euthanasia and they believed to be able to

provide relief for the sick person's suffering without abbreviating his life. The other physicians (16/30) stated that if there were not any way to diminish patients' suffering, they would be open to consider an euthanasia request. Clearly there is not a consensus on the issue and this counterpoint turns discussion important, as ethical implications are significant, even more so due to the fact that people are particularly vulnerable by their situation²³.

Medical ethics, in Europe, generally bases in two currents: one, advocating patients' rights, supporting the end of useless treatment and active euthanasia when requested, and the other, based more in medical duty, allows for only requests that meet some predefined criteria, refusing others²².

Medical practice in Australia, Europe, and the United States aiming at keeping patient's autonomy, requires that patient previously authorizes *non-resuscitation* orders, which would serve to prevent application of basic resuscitation measures in heart-breathing stoppages. When decision by patient is not possible, the family is in charge to do it. Such procedures require moral judgment on patient's life value, which includes his relationships, when delegated to his family although intending to keep patient's autonomy²⁴.

Another ethical-professional dilemma may be perceived when decision on *non-resuscitation*

is left for the physician. In recent study, decisions on eligibility for non-resuscitation orders may not coincide with patient's presumed autonomy, unavoidable the discrepancies between his expectations and instituted medical practices²⁵.

Thus, one may see that health professionals perform a crucial role, both in attending their patients' emotional demands and in carrying out an ethical and human sheltering, even in more adverse situation of clinical practice.

Final considerations

The objective of the article was to show that the *death event* is something complex, full of ethical and professional dilemmas, charged with emotions that need to be worked, and discussed from ethical principles that may be summarized by a small word that matters much for the terminal patient: dignity.

The decision of not extending life is too complex, but the limit to invest is connected clearly to the conception of dignified death allied to full awareness of the limitations of intervention. It seems that the ideal would be listen, feel, and think with the individual that suffers the bitter presence of the unavoidable event of death so from this complex relationship the most possible correct solution may arise for each case.

Acknowledgement in memoriam to Professor Lucilda Selli, recently deceased, whose Bioethics classes came out these reflections, the authors acknowledge the incentive to write this article.

Resumen

Reflexiones legales y éticas sobre el final de la vida: una discusión sobre ortotanasia

El artículo presenta las bases éticas y legales de la ortotanasia. La búsqueda de conocimiento sobre el tema estuvo basada en datos disponibles en línea y en la literatura de imprenta, teniendo como criterio de inclusión la relevancia de los artículos para la discusión de la ortotanasia. Ésta es discutida tanto en los campos de la medicina como de la bioética. Las leyes son debatidas como también la ética y el criterio de la dignidad humana con respecto a la práctica de la ortotanasia. Presenta reflexiones sobre la muerte, los dilemas éticos y las acciones de los profesionales en contextos de enfermos terminales. El prolongamiento de la vida del paciente introduce situaciones muy complejas, pero el límite para intervenir debe ser definido por la concepción de muerte digna, teniendo plena conciencia de la limitación de las intervenciones. La solución más correcta para cada situación debe estar en consonancia con la dignidad de la persona que sufre el inevitable proceso de la muerte, respetando sus decisiones.

Palabras-clave: Muerte. Cuidados paliativos. Bioética. Ortotanasia. Derecho a morir. Inutilidad médica. Eutanasia pasiva.

Resumo

O artigo apresenta as bases éticas e legais da ortotanásia. A busca de conhecimentos esteve baseada em dados disponíveis *online* e na literatura impressa, tendo como critério de inclusão a relevância dos artigos para a discussão da ortotanásia. Discute-se a ortotanásia tanto no campo da medicina quanto no da bioética. São debatidas as leis, a ética e o critério da dignidade quanto à prática da ortotanásia. Reflete-se sobre a morte, os dilemas éticos e as ações dos profissionais em contextos de doentes terminais. O prolongamento da vida do paciente instaura situações muito complexas, mas o limite para intervir deve ser definido pela concepção de morte digna, aliada à plena consciência da limitação das intervenções. A solução mais correta para cada situação está diretamente ligada à dignidade da pessoa que sofre o inevitável processo da morte, respeitando suas decisões.

Palavras-chave: Morte. Cuidados paliativos. Bioética. Ortotanásia. Direito a morrer. Futilidade médica. Eutanásia passiva.

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