Personal autonomy and death

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Abstract

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This work aims at carrying out a bibliographical review about themes such as autonomy, informed consent and death, in order to demonstrate how controversial it is to debate death in a social and professional context in Brazil. It shows that comprehension of the dying process will help professionals to care for the terminally ill, allowing them to pass away with dignity. It also shows that speaking or thinking about this topic gets increasingly difficult, when nothing else is left to relieve suffering before an imminent death. It concludes by considering that patients should have, at such a moment, the right to decide and choose a dignified destiny, either prolonging their agony on a hospital bed or ceasing to exist in the company of their beloved ones.

Key words: Bioethics. Personal autonomy. Informed consent. Death. Choice behavior.

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This work makes a bibliographic review on a much polemic and current topic: euthanasia and its unfoldments. Particularly, it reflects on disthanasia and orthothanasia aiming at the principle of human dignity, considering that there is great need of ethical reflection on polemic issues, both in health, ethics and Law realms, and reflection regarding old problems under a new standpoint.

The first international ethics code for research involving humans – the *Nuremberg Code* – was a response to behavior of Nazi medical researchers, revealed during the war crime trials. This code published in 1947 established standards for carrying out experiments with humans, emphasizing participant's voluntary consent. Thus, to stop such atrocities, ethics on research with humans arose.

When bioethics started, one of its major principles was autonomy, which regards the capability of human rationality to create its own laws.

This means capability that people have to self-govern, to choose, to evaluate own possibilities, rights, and duties without internal or external restrictions. This principle finds practical application in norms of social behavior, such as respecting privacy of others, to provide correct information, to request and get permission to intervene in people's body. It is in this framework that one finds the roots of informed consent.

There was, undoubtedly, new hope for humanity due to the scientific and technological revolution. However, such fact brought in dangers and ethical questioning that require attentive surveillance. Undoubtedly, technological deification and scientific idolatry evidence an effort of medicine to deny death and to change into something remote, showing sometimes disrespect for life. The social revolution in the 1960s projected the layperson to participate in the decision-making process on the problem of when life ends, as in the case of Karen Quinlan.

It is worth remembering that this 21 years old young girl entered at the Intensive Care Unit (ICT) of the New Jersey Hospital in comma due to ingestion of drugs and alcohol, been connected to a ventilator. Neurological exams showed irreversibility of the process. Her parents manifest the desire that ventilator to be withdrawn. The physician did not accept the request, insisting that it was his duty to keep all life sustaining measures. Only a request at the Supreme Court of New Jersey, which considered that the ill-person had the constitutional right to refuse treatment, and nominated her father as tutor, eliminating criminal responsibility for the withdrawal of the artificial supporting means. This case raised praised public discussion on decision of interruption of life sustaining measures, starting, therefore, a discussion about the ethics of death and of dying.

Philippe Áries[1] points in his works different mentalities about death in the West take place throughout history. That one prevailing in current imaginary is that considering death as a prohibited and taboo topic, carrying the idea that it should be fought at all cost, since it is considered as failure and shame. Several gridlocks may occur, in this mentality, regarding communication between patients, family members, and physicians, mostly with the worsening of the disease. It is also in this manner to face and to fight death that some unworthy death may occur, prolonged, with much suffering and often solitary, configuring disthanasia[2].

One of the challenging issues refers to the definition of death. Discussion rise due the difficulty in defining what would be the end of a life. When one speaks of a human body death, our attention seems to turn to the biological death. But the meaning of death of the whole body from brain death suggests a definition that concentrates in the life of a person. One knows that science went toward a totally brain definition of death; its rationale is the idea that to be dead is to become incapable of being a person, which requires a level of conscience, assured by adequate brain functioning.

There was in 20th Century, in consequence of adopting this parameter, the need to develop tests on death, either of the entire brain or of the neocortex. This requirement emerged not only due to the development of the ICU and the ventilator weaning capable of supporting organisms with brain death, but to progress in the transplanting techniques as well, which reinforced the definition of death for the entire brain. The Harvard Commission, in 1968, reached the conclusion that individuals under irreversible coma could be declared as dead. The American Electroencelography Society set criteria for electroencefalographic settings for brain death, which, nevertheless, tried just the definition of death of the entire brain. This is what Torres assures[3].

The definition of death for the entire brain is not evidenced, as there are evidences that the whole brain is not dead, and that some tissues remain alive. Therefore, should one consider the whole brain or just the noble functions? It is acknowledged that higher brain centers as condition for people’s life because they are necessary for even a minimum of awareness. Even if the cerebellum or some of parts are working, they do not assure the existence of an individual on their own because they do not provide awareness. Anyway, the discussion persists as there are arguments that advocate the definition of death guided toward the brain as a whole, and are based in the fact that a less rigorous definition would favor misuse, and others who argument the definition in terms of the death of the noble functions. As there is not unanimity regarding definition of death, for some, in a pluralist society, the solution found would be in pluralism itself, allowing for variations of definitions based in individual and group preferences[3].

The principle of autonomy

In broader sense, the principle of autonomy may be inscribed in the proto-modernity of the first Christian community when it built its self-understanding, breaking away from previous tradition, essentially heathen. In the period before Christian thought, one can speak of autonomy if search for understanding that the autonomy process consists on progressive liberation from purely mystical explanations, which assigned powers to natural forces that intervened in human life, and that men should conspire or become to their own fates [4].

In a more restricted sense, the principle of autonomy should be inscribed in the specificity of modern culture tradition, essentially technical-scientific and humanist-individualist. More specifically, it is linked to the relevance that the individual assumes in modernity, inseparable from freethinking claim, of hegemony of reason in face of religious dogmas, and the weight of tradition..

The meaning of autonomy became to be understood not just as an attempt to apprehend rationally the world but to dominate it, and to submit it to human goals through subjective and independent reasoning. In the beginning of Modern Age, with Descartes, the Self starts to be seen as substance, reality given to an individual who, reflecting about himself, certifies of his own existence. The Cartesian thought, however, was not able to explain the existence of reality, external to the self, except through the metaphysical path.

Kant criticized, in the 18th Century, what he called the Copernicus' spin, the statutes of the metaphysical reality of this self, considering it as impossible while as constitutive element of science, even if inherent to human being. Shielding himself under the influence of Hume's pragmatism, for whom external reality to the individual was a datum, he infers that perception of reality is not independent of the individual, who perceives it and means it, showing that representation of the world and of oneself derives from the individual, not more than the way through which he represents all thinking.. The philosophical perspective inaugurated by Descartes and Kant marked the assumption of the worldview centered in the individual, shaping current imaginary.

The concepts of autonomy and self-determination derive, in large measure, from this perception of the individual centered in himself that emerged and consolidated itself in modernity, and that, regarding the patient-physician relationship, little take part in the professional ethics history. The Hypocrites" oath, for been previous to the building process of notion of the individual, does not even mentions him as it is centered in the duty of the physician's beneficence.

Semantically, autonomy derives from Greek *autos,* which means at same time, self, himself, by oneself, and *nomus*, which means *sharing, law of sharing, use, law*. In this sense, autonomy means properly human competence in *giving oneself one own laws*. The junction of the two terms grants the idea autonomy the meaning of self-government, self-determination for people to take decisions affecting their life, health, physical-psychic integrity, social relationships. Therefore, autonomy refers to human being's capability to decide what is *good*, what is his *well-being*.

In Kantian deontological tradition, autonomy is considered a human being's constitutive propriety, who while autonomous chooses his norms and values, makes projects, takes decisions, and acts consequently. But, the utilitarian tradition, initiated by Jeremy Bentham and John Stuart Mill (who privileges autonomy because it would maximize the general wellbeing in the long term), although it preserves identification between autonomy and individual freedom, does not base in will, but in useful acting. This difference has major consequence because, in accordance to Kantian conception, to inflict the principle of autonomy consists in violating the individual itself, while in the utilitarian conception to inflict this principle may be justified having into account other desirable objectives, useful to the individual himself[5].

Segre, Silva, and Schramm[4] contextualize the notion of individual in contemporary societies associating it to subjectivity not as given attribute, but as constitutive element of becoming that would correspond to freedom exercise itself, that, therefore, expresses also the exercise of autonomy.

In Law, the concept of autonomy is reduced to self-determination. It may be defined as *the capability of making own choices and to undertake actions without coercion*, at least without coercion other than those imposed by law. Or still, according to Engelhardt Jr. [6], is *the freedom to do what is convenient as long as I don't make others suffers something he did not consent*. Ultimately, making a bit of a caricature, autonomy goes back to freedom of doing what I want, to freedom of acting according to my own will, even if other judge my choice senseless. The notion of autonomy goes through the definition of aptitude and inaptitude.

Durand [7] and several authors (jurists or not) stress, in order to be precise in what consists aptitude, three essential elements: i) capability of an individual to understand provided information and on the implications of the act; ii) capability of deliberating on possible choices in function of values and goals been pursued, and iii) capability of clearly expressing own choice.

Thus, autonomy or self-determination is considered a right (right to be informed, right to decide, right to choose) owned by every pondering adult individual or by his representatives, in case the individual himself be legally or psychically incapable.

In ethics, the issue is more complex and again goes back to Kant. Autonomy is a rational agent's propriety, *determined only due to his own law, which is to abide by the duty dictated by practical reason. The fundamental idea is the following: in deliberating in reference to action, one should not only be discussing prudence of this action with the goal of knowing if it is an appropriate means to get some desired goal, but also one should determine if it is intrinsically fair or morally correct.*[8].

Therefore, autonomy opposes both to servitude related external laws (political or moral) and to subjection regarding own wishes and individual whims, subjective. Thus, in ethical sense, autonomy is the capability to decide, but deciding in the sense of good and of what is fair. It is, therefore, a responsibility or duty – the responsibility to reflect about objective demand of respect and of promoting human dignity in myself and in each being; the responsibility to choose an action that follows the sense of respect to each and every human being [7]. One may define briefly, then, autonomy according to the following table.

Table I: View of autonomy for oneself and for someone else

For oneself	Regarding someone else
In Law	
– capability to make own choices – freedom to act according to own will – right to decide on what is convenient	To respect his choice, whichever it may be
In ethics	
– duty to act responsibly – responsibility to choose an action that inscribes in the sense of respect to each and every human being	To help making a responsible choice

Source: Durand G. Op. cit.; 2003. p. 179.

MacIntyre divides autonomy into three types: of thought, of will, and of action. Autonomy of thought includes the capability to take decision and to have critical opinions. Autonomy of will is the possibility to deliberate from the freedom that one has to decide, while that relative to action results from junction of the first and the second and it suffers restrictions, since one lives in society in which the possibility of having impediment of internal or external order may take place [9].

Autonomy as human capability does not cancel the influence of external forces or actions based in impulses, it involves degrees and it has three elements: determination, independence or freedom, and reason. The first, determination, makes that individual to be aware of own wishes and seeks to meet them. This capability Is what distinguishes humans from objects and animals – these later show needs, but do not have awareness of itself, as carriers of such needs and that they need, in order to meet them, to depart to a planned action. The second, is independence or lack of controlling influences. People that live under coercitive situations and/or manipulated have little or no autonomy capability, which in order to be exerted require a reasonable range of options. Even considering that external influences will exist always, those that harm autonomy are those that include coercion and manipulation. It is worth considering that, according to Engelhardt Jr.[10], who advocates the moral strangers theory, each individual has his life and legitimate moral conception based upon principles and hierarchies of the moral community. Therefore, nobody has the right to impose to others his life style and conceptions about what is good or bad, or to limit expressing such conceptions.

The third element regards the capability to make decisions based in reason, which makes humans to have capability of reflections and take alternative decisions. This identification between will and reason is what may make humans a totally free being.

It gives birth to a notion that perpetuates itself in Western tradition as fundamental principle of moral life and personal identity: autonomy[11].

One verifies the existence of several features related to the definition of autonomy, but the one repeated most often regards rationality, taken as the legal capability of making decisions. The concept of autonomy, therefore, implies some circumstances, such as: rationality, capability, independence from external and internal controls, freedom of option and subjection to own action plan[12]. Miller, Almeida, Beauchamp, and Childress reinforce such perspective by pointing to the issue of understanding: if there is not understanding of the situation, there will not be autonomy[13,14,15]. Autonomous individual, therefore, acts freely in accordance to a plan chosen by himself, and he should decide based in own beliefs and values, even if different from those predominant in the society in which they are inserted.

There are situations, however, in which autonomy decreases as it happens with children and adolescents. Since they are considered as not having competence to decide, they are legally incapable and, as consequence, do not have autonomy to make rational choices. There is the need that other people decide for them, in this case parents, who besides knowing their children, they are motivated by love, having thus more interest in their well being. In this situation, decision-making should be always a shared responsibility among team and parents. In Brazil, the Statutes of Children and *Adolescent*[16] (ECA) is the legal instrument targeted to ensure the rights of people in that age group, and it may be used when there is evidence of power abuse by parents – when these deny children the right to health. When child becomes older and more capable, he/she should be included in the decision-making process, along with his/her parents.

Institutionalized people (inmates or mentally disabled) may have their autonomy reduced. Mental incapacity limits the autonomy of disability carriers, as well as the coercitive institutionalization hinders inmates' autonomy. Practically all autonomy theories consider two core conditions: liberty (independence of controlling influences) and actors' quality (capacity of acting intentionally) [5].

From exposed one takes out that autonomy is one of the pillars of fundamental rights of Man and, specifically, of the rights of his personality, foreseen in national magna charters that consecrate the exercise of citizenship. In Brasil, citizenship awareness of retaken with the upcoming of the Federal Constitution[17], which renewed the fundamental rights of Man: the right to life, to physical integrity, to parts of his own body, to freedom, and of action. Personality rights were also rescued, those related to respect and moral preservation of human being: right to honor, to the name, to image, to secrecy, to freedom of conscience, and of cult [18].

Informed consent

Informed consent, in its Anglo-Saxon traditional expression, or clarified consent, in a reformulation proposal for the original expression by part of a Latin Europe, or simply *consent*, keeping different actions at margin of the polemics regarding its scope, it designs an individual's explicit accordance to a biomedical action proposal related to his health status. It acquires different specifications as it reports to medical investigation or clinical practice scope. The effective act of consent will be *conscious* (the individual is competent according to psychic and legal perspective for the accurate, concrete and singular features to what his authorizations refers); *clarified* (the individual duly understood the information given on procedure and on its individual secondary effects), and *voluntary* (the individual is totally free to give or to decline his consent at any time of the process in question).

Currently, the origin of notion of consent in the realm nominated as biomedical is, as it is known, legal. The event that marks its genesis occurred in 1914, in the United States, in reference to the *Schloendorff's* case, who complains of the removal of a tumor without his consent, and the Courts stated *on right that every human being of adult age and mentally healthy has to determine what will be done to his body*. After this case, others emerged until law jurisprudence was constituted. It was the *Nuremberg Code* [19] that set as mandatory getting patient's consent, reinforced by the *Helsinki Declaration*[20], which required that consent to be stated in writing [21].

As consequence of consolidation of bioethics basic principles and, among them, autonomy, defined as respect for the individual, it was developed the necessity in medical acting the duty to inform patient and to get his/her consent to legitimate the needed intervention. The requirement of informed consent synthesized the respect for patient's autonomy, being broadly acknowledged in medical ethical codes of many countries and, even in specific legislation, mainly when one identifies the decrease of this autonomy by diverse reasons, age or deriving from the development of the disease itself [22].

Informed consent, in bioethics plan, lies on the patients' autonomy who manifest in choosing health professional, in acceptance or declination of proposed therapeutical measures. Traditionally, physicians, health professionals, can influence in patients' decision-making, but they do not have the right to impose their will on them. This influence, derived from professional training, is controlled through the clarification practice provided to patient regarding his disease, to indicated therapies, prognosis, side effects, so his consent is based on intelligible information. This is what is called *informed consent.*

The informed consent principle bases in the individual, to his autonomy aiming at avoiding the professional's supremacy, and to preserve freedom, but it fosters rational decisions of who, ultimately, shall withstand the effects of treatment[18]. The act of consenting should be genuinely voluntary and based in adequate revelation of information. In this sense, it encompasses information and consent elements. Of the first, revelation of information in accordance to individual's level of intake and his adequate understanding takes part; of the second, the voluntary consent and the competence for consenting. Three conditions determinate competence: i) capability to undertake choices based in rational criteria; ii) capability to achieve reasonable results through decisions; iii) capability of decision-making [23]. All patients have the right to receive, from the professional chosen to assist him, sincere and detailed information on their health. Besides, his informed consent should be obtained freely and without any coercion.

Concerning children, adolescents, and the mentally disabled, who do not have competence to decide or autonomy to make rational choice, it should be considered that other people decide for them – but, whenever the level of understanding allows for their participation, their decision should be respected. Concerning an adult with loss of awareness or in coma, it should be checked if he explicitly expressed his will previously; otherwise, it could be known from family members if there is patient's presumed will.

In Brasil, Article 15 of 2002 Civil Code[24] sets forth that nobody can be constrained to submit himself, with life at risk, to medical treatment or surgical intervention. Information is considered, also, a human's fundamental right, set in the 1988 Constitution of the Federative Republic of Brasil [17], in the domestic scope, as well as in the *Universal Declaration of Human Rights*[25], in the *Universal Declaration on Bioethics and Human Rights*[26]. and in the *Geneva Declaration*[27], among other human rights international instruments.

Regarding specifically to the biomedical area, the National Health Council approved Resolution 196, in October 1966, which regulates research involving humans. In its item 11, it defines free and clarified consent as *research subject's agreement and/or of its legal representative, free of any vice (simulation, fraud or error), dependence, subordination or intimidation, after full and detailed explanation on the nature of the research, its objective, methods, foreseen benefits and annoyances that it may bring, formulated in a consent term, authorizing its voluntary participation*[28]. Item III.1 clearly states that researches must respect the principles of autonomy, of beneficence, of non-maleficence, of justice, and equity.

Palliative care

Non-satisfaction with practices of modern medicine dominant stream, particularly at the end of life, explains the establishment of the *hospice* (shelters targeted to comfort and care of pilgrims and travelers evolved and began to have hospital features).

In 1967, with Cicely [29], began the Modern *Hospice* Movement. In 1982, the World Health Organization (WHO) Cancer Committee created a working group to define policies aiming to alleviate pain and *hospice* type care for cancer patients, which would be recommended to every country.

The term *palliative care* began to be adopted by WHO, in view of the difficulty to a faithful translation into some languages. The definition of the term emerged in 1986, as: *active and total care for patients whose disease is not responsive to curing treatment.* Pain control, and of other symptoms and of psychosocial and spiritual problems are primary. The *objective of the palliative* care is to provide the best possible quality of life for patients and family members[30]. In 2002, this definition was reviewed and replaced with the objective to expand the concept and making it applicable to all diseases.

Palliative care principles based in scientific knowledge inherent to several specializations and possibilities of clinical and therapeutical interventions in many areas of medical science knowledge. They do not reject modern scientific medicine, but they expand basic medical theory in order to correct some of its worst distortions. Palliative medicine seeks to achieve three interrelated goals: i) effective concentration in pain and suffering and on their care; ii) concern both with body condition and with patients' inner life; iii) the decision process that respects patients' autonomy, and the role of its legal representatives.

The philosophy of palliative care seeks to make health professionals aware of limitations inherent to professional practice, fostering them to stop thinking the end or chronic disease as medicine failure, and inciting them to reconsider on the importance of pain and suffering relief – classical goals of medicine. In this context, dignified ending may be defined as that without pain and minimized suffering. Symptoms should be controlled and quality of life preserved for the patient without curing function, of prolonging or abbreviation of survival rate.

In the dominant contemporary medicine one uses science to define the disease and to develop effective therapeutical interventions. It used to be impersonal. The palliative care specialization breaks this incomplete perspective and takes again as target the whole person of the patient; it corrects a series of faults, conferring to modern medicine a needed expanded view. There is not any cure to death, but the best and most effective palliative care is offered by physical pain and suffering relief, in a compassionate and sensitive way.

Death

Death is defined as the definitive cessation of life in the body. Dying may be delimited as the process that takes place between the moment in which disease becomes irreversible and that when the individual does not respond to any therapeutical measure, inexorably progressing toward the final of his existence. The word death associates to feelings of pain, suffering, separation, and loss. Modern Western civilization runs away from this sort of feeling, consequently, eluding from death.

The definition of death and the way to face it varies in accordance to approach and the philosophical, religious, medial, and legal study, but concepts are not crystallized in all these fields of study and reflection: the world of laws reinvestigates, at all times, the causes and ways to deal with the death event. Medicine, the more it deepens in the mysteries of human body, and the less it accepts not been able to control them, sets new systems of study and of determination of when human being really may be considered *dead*, since death is not an instant but a process in which one identifies phases: brain, biological, and clinical death.

Death entered, in 21st Century, in the high technology age, and it may be qualified by five features: 1) a *prolonged act,* generated by technological development; 2) a *scientific fact,* generated by perfecting monitoring; 3) a *passive fact,* since decisions belong to physicians and family members, and not to patient; 4) a *profane act*, for not attending patient's beliefs and values; and 5) an *isolation act*, as human dies socially in loneliness. Generally, Western societies do not see death as part of life, but rather as a punishment, something unacceptable and, therefore, an issue to be avoided socially.

In face of representation of death, which may aggravate, inclusively, terminal patient's pain and suffering, the *Society of Critical Care Medicine* Ethical Committee established a consensus to define what would be useless treatment, and which procedures should be adopted. This committee published a compilation of ideas in which it was verified the importance of patient's prior positioning, as well as a communication between health team, the patient, and his family [31].

This compilation is fundamental for the exercise of a compassion medicine, targeted to human being, as it must be understood that physician's intervention power grew considerably without existing a simultaneous reflection on the impact of this new reality in the quality of life of the ill people, been unnecessary to comment on the benefits achieved with the new diagnostic and therapeutical methodologies. One clearly realizes, then, (throughout the entire study) that medicine and technology conjugate.

At first sight, one could think naively that death in the hands of modern medical technology would be a less suffering event, more gracious, at last, more so than it was in Ancient times. One can argue that nowadays there is: i) more knowledge regarding physical-biological processes of the human body, which allows us to issued accurate diagnosis of death; ii) analgesics claimed as from the *last generation*, which increase the possibility to control pain; iii) more sophisticated machinery, capable to replace and control organs that enter in failure; iv) greater psychological knowledge, a precious instrument to alleviate anxieties and suffering of an anticipated death. Wouldn't it be what we need to turn reality the possibility of a dignified and peaceful death?

The answer to these questionings could be both *yes* and *no*. *Yes*, because there is more knowledge than at any previous age. But *no,* because this knowledge did not make death a dignified event as well. Biological knowledge and technological skils made human dying more problematic, difficult to foresee, more demanding to deal with it, source of complicate ethical dilemmas, and highly difficult choices, therefore, anguish, ambivalence, and uncertainties generator. It is not a question of advocating here an opposing stand regarding technological medicine, but against *technolatry*. The challenge is to reflect how the binomial technology-medicine relates with human mortality, and how it can help to turn dying in peace a reality.

Professionals who are not prepared for the issue begin to practice a medicine that underestimates the comfort of sick person with incurable disease in terminal patient, imposing on them long and suffering agony. Death is postponed, in many cases, at the cost of senseless and prolonged suffering for the patient and his family. Finitude of life is a condition diagnosed by physician before a patient with incurable disease, one understands that there is a disease in its terminal stage, and not a terminal patient. In this case, priority becomes the sick individual and not treatment anymore.

If, inevitably, each human life comes to its final, one should ensure that this passing occurs in a dignified way, with adequate care that seeks the lesser possible suffering.

Euthanasia

Derived from Greek *eu* and *thanatos* is the word used to express that physician should calm down suffering and pains not only when this relief can provide cure, but also when it can be used to seek for a sweet and ease death [32]. This term created in the 17th Century, in 1623, by the philosopher Francis Bacon, as having the adequate treatment for incurable diseases, understood as a good death.

There are some relevant points that should be considered under euthanasia generic concept. These points imply the need to distinguish different ideas and practices that are metaphors of the word under issue. Currently, the most useful modalities to classify euthanasia base themselves in the *act itself*, and in *patient's consent*. Euthanasia can be, regarding the act, active, passive, and of double effect, while in active euthanasia there is plan and actions aming at ending life, since it is planned and negotiated between patient and the professional or relative who will undertake the act [33].

Passive euthanasia[32], in its turn, does not cause death deliberately. However, with time, interruption of all and any medical, pharmacological or other care, patient ends dying. Double effect euthanasia (technical term used in Ethics regarding two possibilities of consequences resultant of use of a special action, nominated as desired effects and undesirable paraeffects) occurs in cases when death is accelerated as consequence of medical actions not aimed and lethal success, but rather to alleviate a patient's suffering.

Concerning patient's consent, euthanasia can be voluntary and non-voluntary. Voluntary is the response to patient's expressed desire, which would be synonym of assisted suicide; involuntary, when the act is undertaken against patient's will, and in general lines it can be equal to homicide; non voluntary is when life is abbreviated without knowing patient's will.

One can conclude from this set of assumptions that euthanasia is medical action or omission applied to a patient's request, with his consent or previous legal regulation, by piety and humanitarian compassion to surpress or to abbreviate long, painful, and inevitable agony of someone who suffers of incurable disease, and is waiting for death.

There are many opposing and supporting arguments for euthanasia. Those opposing are centered in the sacredness of life principle, and in the *slippery slope* argument. According to the sacredness principle, life consists of a good, granted by divinity or by manifestation of nature's intrinsic final solution. Despite been considered as one of the most scathing objections to euthanasia, mostly in Christian ethics and in Hippocratic tradition, a question imposes if life really is a good, who would be competent to judge this *beatitude*? Wouldn't such prerogative fall over the holder of existence itself?

In the de *slippery slope* argument, justification would be that apparently innocuous concessions should not be granted in order to open precedent for unequivocal malefaction attitudes, herein included: mistrust and subsequent worn out of the physician-patient relationship; possibility of acts not inspired in altruist goals, but motivated by other reasons (inheritance, pensions, and others); psychic pressure that would let patients, whose death is approaching, without perspectives other than euthanasia, actually not desired, and, therefore, imposed somehow for circumstantial reasons; and the definitive erosion of respect for human life.

Supportive arguments center in the quality of life and personal autonomy principles. The quality of life is a general principle with *prima facie* validity, applied only under certain circumstances and, consequently, without universal and unimpeachable value. It states the existence of a value for life, applied only if this is provided of a certain number and level of historical quality socio-culturally built and accepted by the holder of a private life. More controversial issues related to quality of life refer in determining which is the real meaning of a life that worth living and to who should be given the prerogative to decide about such meaning.

According to Kantian thought –for who the genuine moral act should be conceived in full exercise of freedom of the ethical subject – the interested in living should be decide on his own life and death. Such instance leads to personal autonomy issue, considered as the most important principle to legitimate euthanasia.

Disthanasia

The term *disthanasia etymologically has the idea of double death*. It is understood as the maintenance of life by means of disproportional treatments, leading to a prolonged dying process with physical or psychological suffering, i.e., deepening of characteristics that make, actually, death a sort of hyper-death.

The term may be used also as synonym of useless treatment. It is the medical attitude that, aiming saving patient's life, submits him to great suffering. This practice does not prolong life itself, but the dying process. In Europe, one defines this process as *therapeutical obstinacy*; in the United States as *medical futility*. In more popular terms, the issue would be set as follows: until which point should the dying process be prolonged when there is not anymore hope to revert the picture? Who has the interest in keeping the living-dead individual? [34]

In summary, disthanasia is the artificial prolonging of the death process with patient's suffering.

An instance when one artificially prolongs agony, even if medical knowledge, at the time, does not foresee the possibility of cure or improvement. t is the expression of therapeutical obstinacy for treatment and technology without due consideration for the human being.

Orthothanasia

The concept of orthothanasia emerges in opposition to disthanasia, and etymologically it means the correct death: *ortho* = correct and *thanatos = death*. Orthothanasia implies in the artificial non-prolonging of the death process beyond the natural process. It indicates death at its right time, neither before nor after. In orthothanasia, there is omission or suspension of measures that have lost their indication since they result useless for that individual, in the level of sickness that he is. The basic care is kept.

Studies and discussions allow to state that orthothanasia is sensitive to the humanization process of death and relief of pains, and it does not incur in abusive prolonging with application of disproportionate means that would impose additional suffering [36]. One understands that the physician is not forced to prolong patient's dying process by artificial means without his request to do so.

The right to life does not imply in survival obligation, additionally to the natural period, through measures that often are worn out and painful, placing a serious threat on patient's human dignity. The adoption of such measures often extrapolates what should be in his benefit and enters in the realm of mere therapeutical obstinacy. It is important that, when medical practice is not capable anymore to accrue effective benefits for the patient, at least, to not increase his suffering through undue and obstinate just to prolong terminal existence.

The fact that patient does not have indication for extraordinary measures or considered disproportionate, it does not mean that one should not have less attention with his well-being. Basic care should be kept, as proportionate measures that they actually are, and as internationally acknowledged rights to sick individuals. Considering the Brazilian framework, a brief mention to the Federal Council of Medicine (CFM) Resolution 1,805/06 should be made, which set forth: "*At the terminal phase of severe and incurable diseases, it is permitted to physician to limit or suspend procedures and treatment that prolong patient's life, ensuring him the necessary care to alleviate symptoms that lead to suffering, within the perspective of integral assistance, respected patient's or his legal representative's will*"[36].

This resolution was target of criticism from the public section, unfunded as I see it, which culminated with its suspension due to an injunction in 2007. Therefore, the resolution does not permit anything currently, and it only rectifies what is permitted already. It just clarifies some common doubts that physicians have when dealing with terminal patients, when stating the conclusion –somewhat obvious – that nobody is forced to die intubated, using vasoactive drugs in an ICU. This resolution, without reinforcing suicide or homicide intentions, sought just to safeguard declination of technology when it is not any longer beneficial. Orthothanasia, advocated by the resolution, proposes protection to intimacy, privacy, and licit autonomy, to dignity itself. One does not anticipate death, but allowing it to come in its due time.

Final considerations

Although death is, unarguably, an universal phenomenon, since Man is to his condition of been finite, the review on its meaning in several cultures and religions allows for checking that its representations undergo significant changes in time and space. A fact that can be seen throughout the history of humanity. In Western culture, the breakage occurring since the second half of the 20th Century, when death stops been *familial, domestic, and becomes a taboo*, changing it into something that post-modern Man tries to run away from, in order to not dealing with his own finitude. However, his condition as mortal does not allow that this runaway be successful, as death is part of the vital cycle, thus Man will have to deal with the death of his beloved ones and, finally, to face his own.

The reflections about death get special relief in this medical context, in which the act of dying takes place in the public realm, even when death happens in flagrant loneliness. The fact that death may take place in public space, hospitals, leads to health professionals, in general, Saúdeand the medical team assisting the patient, specifically, to reflect and act in face of this situation, unavoidable to every and any live being.

One knows that the patient, as individual, has all conditions to know what is best for him. The autonomy concept in physician-patient relationship implies that both parties are competent to evaluate possible options, and to make a conscious choice. It happens that, in certain cases, choice shall be made only if patient is duly instructed and, therefore, the procedures to be taken must be detailed, clearly and comprehensively. One knows that physician and team can only undertake certain procedures with patient's consent. But, the question is, would it be that this is actually enforced?

When one considers the autonomy issue and patient's competence, it seems that they easierly accepted when physician's and patient's opinions are coincident. The complication emerges when opinions are in disagreement or if patient does not wish to be submitted to certain treatments, mainly when decision involves death risk. There is, then, the issue: what is more important for an individual: a life with better quality, although short, or a longer life with suffering and limitations?

One notes that, in many cases, mainly among destitute classes, the patient does not have knowledge of his status, he does not know what is happening and, due to used language when procedures are presented to him, they are not capable to understand. In other cases, total competence is attributed to physician, which derives from the idea that his action should never be questioned. Some patients think that if they question him, they will take the risk of not been assisted anymore, of been abandoned or referred to another professional. It is known that many feel thankful for been assisted and, consequently, they think that they do not have the right to exert his autonomy, since it would imply in disrespect in relation to the professional.

As previously explained, in order to autonomy be exerted, it is necessary that patient be guided, that he has needed information for decision-making. It is necessary, for it, that he feels competent, capable of taking life as his responsibility, and he wishes to do it in order to people surrounding him and, mostly, the medical team, to confer him this competence.

It becomes possible, in face of the exposed, to infer a few stands on the issue: the suspension of resources that artificially maintain organic balance is not offense against life. Nowadays, one claims re-appropriation of death by the sick himself. There is the concern on safeguarding the individual's quality of life, even at his death time. One claims for a dignified death, which means refusal of submitting to technological maneuvers that just prolong agony. *It is an appeal to the right to live a death with human features* (...) it means the desire of re-appropriation *of his own death, not object of science, but subject of existence* [37]

Therefore, the study under issue leads to stating that the three hypothesis of euthanasia, disthanasia, and orthothanasia refer to situation in which there is an incurable disease and unbearable physical suffering, distinguishing one of the others by the intention of who produces or omits to prevent death (agent's intention), through the employed mode and means, even if painless. In parallel, *suspension or abstention of artificial hydration and feeding requires deep discussion, involving debates on individual right and law, since it regards wishes, yearnings, decisions, and choices*. It involves conflict and, thus, additionally to moral issues, it relates to ethical features.

For those who defend life at all costs, the suspension of artificial hydration and feeding, even in irreversible patients, is seen as euthanasia. Those who favor it see prolonging of treatment in irreversible situations as an attempt against life. There are many considerations and answers, depending on the standpoint about the issue, and they involve the patient, his family, and the assisting team and institution.

Such polemic and deep questionings have guided discussions about to what point the dignity of an individual is respected in limit situations, leading to questioning *if the artificial prolonging of life, even if just vegetative, does not represent a manipulation that violates human dignity and, if certain unnecessary coactive treatments offend the individual's dignity*[37].

ÉIt is of utmost importance that patient is involved in the decision-making and well clarified process on the circumstances related to terminality of his life, prevailing in this decision patient's manifested will – when it is not possible, the *best interest* should prevail. In countries with the same cultural tradition, legalization of the Anticipated Directive of Will would be important for individual rights affirmation [38].

Thus, if patient's condemnation is certain, and if death is unavoidable, is life been protected? No. We state that there is postponement of death with suffering and indignity [...] If life and death are non dissociable and as the last one is one of the most heightened moments of life, there will not be up to the human being to dispose about it, as it disposes about his life?

Resumen

Autonomía personal y muerte

Este trabajo tiene como objetivo revisar la literatura existente sobre temas de la autonomía, el consentimiento informado, la muerte, demostrando cómo hablar sobre la muerte es motivo de controversia en la sociedad brasileña y profesional. Sostiene que la comprensión del proceso de la muerte ayudará a los profesionales para ayudar a sus pacientes en su muerte y el respeto de su dignidad. También apunta a hablar o pensar acerca de este problema se hace más difícil cuando no hay más por hacer para aliviar el sufrimiento frente a la muerte inminente. A conclusión considera que teniendo en cuenta que en este momento las personas deben tener derecho a elegir y decidir su destino con dignidad, prolongar su agonía en la cama de hospital o morir en compañía de sus seres queridos.

Palabras-clave: Bioética. Autonomía personal. Consentimiento informado. Muerte. Conducta de elección.

Resumo Este trabalho faz revisão bibliográfica sobre os temas *autonomia*, *consentimento informado* e *morte*, demonstrando como é polêmico discutir a morte no contexto social e profissional brasileiro. Argumenta que a compreensão do processo de morrer ajudará os profissionais a amparar os pacientes na sua morte e a respeitar sua dignidade. Aponta também que falar ou pensar sobre esse tema torna-se mais difícil quando não existe mais o que se fazer para aliviar o sofrimento frente à morte iminente. Conclui considerando que neste momento as pessoas deveriam ter o direito de escolher e decidir com dignidade o seu destino, prolongando sua agonia em leito hospitalar ou morrer na companhia de seus entes queridos.

Palavras-chave: Bioética. Autonomia pessoal. Consentimento livre e esclarecido. Morte. Comportamento de escolha
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