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Abstract

The concept of "dysthanasia" is still partially known in the world academic community. The concept is opposite to the concept of "euthanasia", incomparably more often mentioned, but without doubt much less often practiced in health-care institutions, especially in intensive care units. The objective of this article is to expound fundamental theoretical and practical aspects of dysthanasia, as well as to encourage discussion about this actual topic. The article discusses the position of dysthanasia within the objectives of contemporary medicine, as well as according to the definition of health by the WHO the definition of illness by the Hastings Center and the Recommendation No. 1418 of the Council of Europe Parliamentary Assembly. It concludes with comments on certain examples of possible dysthanasia from the world history and two actual examples from our clinical practice.

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Dysthanasia: the (il)legitimacy of artificially posponed death

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Abstract:

The concept of "dysthanasia" is still partially known in the world academic community. The concept is opposite to the concept of "euthanasia", incomparably more often mentioned, but without doubt much less often practiced in health-care institutions, especially in intensive care units. The objective of this article is to expound fundamental theoretical and practical aspects of dysthanasia, as well as to encourage discussion about this actual topic. The article discusses the position of dysthanasia within the objectives of contemporary medicine, as well as according to the definition of health by the WHO the definition of illness by the Hastings Center and the Recommendation No. 1418 of the Council of Europe Parliamentary Assembly. It concludes with comments on certain examples of possible dysthanasia from the world history and two actual examples from our clinical practice.

Key words: bioethics; death; medical futility; personal autonomy

Problematics of death and dying have always been, like the issue of the life's inception, one of the leading subjects of scientific discourse, not only from philosophical and religious standpoints, but also in the medical setting where such practical aspects of these two phenomenons are met daily. The best approach to these problems is an interdisciplinary and multidisciplinary one, precisely according to its bioethical character, taking the personal autonomy of the patient as a basic guideline (1, 2). In other words, it is necessary to draw away from the medical-ethical simplification that reduces and shortsightedly places the problem on two basic viewpoints: pro or against (3).

How to Define Dysthanasia?

Searching the Medline with the term "disthanasia" offers data on only two scientific papers, while searching with the term "dysthanasia" offers data on ten (4-15). The papers were written in four time cycles: seven from 1970-1975, one in 1983, three from 1991-1995, and the most recent in 2001. With regard to the context within which dysthanasia is contemplated, they can be divided into four thematic groups: 1) general philosophical-medical contemplation (4-12); 2) dysthanasia in geriatric psychiatry (13); 3) dysthanasia in traumatology (14); 4) dysthanasia in oncology (15).

What does the term dysthanasia include? Leo Pessini, the author of the book "Dysthanasia: Until when to prolong life?" defines dysthanasia as a "slow, painful death in immense suffering," in other words "merciless prolongation of life" (16), but the first bioethicist who used that term and suggested that it be used within bioethics was Leonard M. Martin (17). The term in question is a neology of Greek origin, in which the prefix *dys* signifies a "wrongful act." Therefore, dysthanasia etymologically signifies exaggerated prolongation of agony, suffering, and death of the patient. The concept can be employed as a synonym for futile and useless treatment, that consequently medically assists slow and prolonged death followed by suffering. Such behavior does not prolong life – considering its quality – but the process of dying. For such situations the French syntagm of "therapeutic perseverance" (*L'acharnement thérapeutique*) is most often used in Europe (18). In the USA "medical futility," "futile treatment," or simply "futility," are most often used (19-25). When discussing dysthanasia it is commendable to employ the syntagm "futile treatment" (16). The directly imposed issue in this context is: until when to prolong the process of dying when there is no longer hope for life, when in such a phase of illness each therapeutic process only postpones the inevitable and prolongs the agony and human suffering? Who benefits from keeping a person "dead-alive?"

Euthanasia lies on one end as a "merciful death," and on the other lies dysthanasia as a "merciless prolongation of agony, suffering, and postponing of death." Between these two extremities is an attitude that respects the human dignity and protects life, and which many bioethicists define as "orthothanasia." Using the Greek prefix *ortho* (=correct), orthothanasia embodies the meaning of death "in due time", without unnecessary shortening nor prolongation of the process of dying and without additional suffering (16). Unlike euthanasia or dysthanasia, orthothanasia may be thus considered as a step toward the humanization of the process of dying.

The Position of Dysthanasia Within Objectives of Modern Medicine

Medicine that simultaneously strives to be honorable, balanced, accessible, supportive, and unbiased continually needs to contemplate its objectives (26).

Health is something that each individual possesses to a greater or lesser degree (27). Achieving the highest degree of health is one of the basic rights of a human being (28). It is understandable that man has been striving for thousands of years to attain this state of health, and if possible, to maintain it (26). Oppositely, the concept of infirmity could be defined by four notions present in the English language: malady, disease, illness, and sickness (26). "Malady" presumes various conditions – besides illness – that threaten health. It includes deficiency, injuries, and defectiveness. Thus it is possible to define "malady" as a condition in which a person suffers, or there exists a danger that he or she will suffer from any kind of harm. "Disease" is poor physiological or mental functioning, according to statistically standardized norms, that causes illness, deficiency, or increases the possibility of premature death. "Illness" is a subjective feeling of a person whose mental or physical well being is absent or weakened, in other words, his usual functions are weakened. "Sickness" is the perception society has on health conditions of an individual. In general, it is the external perception that a person is not well mentally or physically.

Taking into account the quoted concepts, it is possible to analyze three basic objectives of medicine (26). The first is to *save and prolong life.* However, what does that goal signify today, within the modern medical technology, when there is equipment available that can maintain a body alive "until further notice?" Where are the limits to which medicine can and may prolong life, and who is the person who will be able to, have a right to, and know how to say: enough! One of Potter's definitions of bioethics is that bioethics should be the controller of science and warn us if science nowadays has the permission to do all it can do (29, 30). Does this definition gain in significance and concrete, practical use within the context of discussions on dysthanasia? The second objective of medicine is to *improve and maintain health.* But, what does this mean in an era in which a prematurely born child that weighs less than 1,000 grams or a geriatric patient that has lived to be 100 years old can attain health? Do we truly do not wish to (or cannot) accept the concept of illness and death as the integral part of life? The third traditional objective of medicine is to *palliate pain and suffering*. Does this mean that euthanasia, dysthanasia, and medically assisted suicide should be accepted as integral parts of medicine? The question that simply needs to be asked in this context is: what is the legitimate area of medicine and where to set the limit that legitimates any sort of medication?

Dysthanasia in the European Context

On its Parliamentary Assembly on July 25, 1999, during the 24th session, the Council of Europe adopted Recommendation No. 1418 that refers to the *Protection of human rights and dignity of the incurable and terminally ill* (31). This document specifies an array of factors that nowadays endanger the dignity of an ill human being, in incurable and terminal conditions: 1) lack of access to palliative care; 2) absence of physical treatments and disregard of psychological, social, and mental needs; 3) artificial prolongation of the process of death, whether by employing a treatment inappropriate for the patient's condition, or by continuing treatment without his consent; 4) nonexistence of continued education and psychological support for health workers that deal with terminal patients; 5) insufficient support to family members and friends of terminally ill patients; 6) insufficiency of financial funds and resources; 7) social discrimination of those who are objects of debility, agony, and death (31).

The Assembly of the Council of Europe forwarded an appeal within this reference to member states to ensure that the incurable and terminally ill patients get a necessary legal and social protection against the dangers, specially against risks of: 1) a person being a victim of intolerable symptoms upon the approach of death (pain, suffocation, etc.); 2) prolongation of

their lives contrary to their will; 3) dying in solitude and abandonment; 4) ending their lives in the fear of being a burden to society; 5) lack of artificial means for survival due to economical reasons; 6) lack of necessary means for the care and support of incurable and terminally ill patients (31).

The Council of Europe document concludes with a vast range of recommendations for member states to respect and protect the dignity and life quality of incurable and terminally ill patients. The recommendation also takes into account the humanistic component from the 1948 Declaration of Human Rights, and the knowledge and consideration of bioethical matters through emphasizing one of the four fundamental bioethical principles – personal autonomy of the patient (1,2). There is a strong emphasis on palliative care on one side, and stressed reproach of futile treatment, on the other side. The general aim could be the introduction of the philosophy of palliative care into the context of the health system, medical humanities, and medical education in general.

Examples of Possible Dysthanasia From the World History

It is necessary to mention that Pessini (16) states the case of the Brazilian president, Tancredo Neves, who died in 1985 as a particular example of dysthanasia. Namely, the author, from immediate proximity, observed the long-lasting agony of president Neves passing away, acting as a hospital chaplain at the Hospital Clinic of the Medical Faculty of the University of São Paulo 1982-1993 (16).

Pessini (16) goes even further, calling for deliberation on cases of other famous historical persons such as Truman, Franco, Tito, and Hirohito, that could also be defined as futile treatments, ie, cases of dysthanasia, taking into account that all of them were kept alive for some period of time on medical apparatus "beyond natural limits" (3).

Cases

Case one
Age 54, Male, Caucasian
April 2003
Diagnosis: Ascendant colon adenocarcinoma - right side hemicolectomy and ileotransversal anastomosis due to colon adenocarcinoma (Dukes C); partial omentectomy due to peritoneal carcinoma; retroperitoneal infiltration; abdominal lymph nodes metastasis; metastasis of the liver.
From 05-09/03 the patient was receiving chemotherapy with a good effect upon his clinical benefit. He was feeling well (Karnofsky Performance Status (KPS) was 100%).
At 09/03 the patient developed cerebral metastases (many lesions from 5 to 22 mm in almost every part of the brain). We also noticed multiple metastatic lesions on the ribs, vertebrae, and in the scapular region.
Patient continued receiving chemotherapy and underwent radiotherapy.
At 11/03, patient reported feeling bad (KPS was 30-40%). He developed multiple metastatic lesions in the lungs as well and a malignant right pleural eflusion. He was dyspnoic and pleural evacuation was performed. We advised the «best supportive care» to the patient (liquid supplement nutrition, megestrol acetate, corticosteroids, pain therapy, dodronat) and only for palliative purposes, chemotherapy with capecitabine per os.
Patient started to follow macrobiotics and to consume vegetarian food, and he lost on weight.
In 03/04, new metastatic lesions were noted: in the sacral bone, in almost every vertebra and in the left femoral bone. He again underwent palliative (antipain) radiotherapy and received

new chemotherapeutics (with no recommendations that that medication had any benefit in those stadia of the disease).
From 04/04 until his death in 07/04, the patient was hospitalized twice. During transportation to the hospital and back home, he was screaming out of pain. His bones were «crumbling». During the stay in the hospital, the pain was not treated properly and his leading physician was not included in the team (she would have not agreed with unnecessary transportations and hospital treatments only because «the family wants it that way»). Patient died at full consciousness, with terrible pains, under infusions and oxygenated (07/04).
It is our opinion that the patient was dysthanased for at least 4 months.

Case two
Age 48, Female, Caucasian
April 2002
On 04/02 omentectomy, hysterectomy, and bilateral adnexectomy were performed due to metastatic mucinose carcinoma (PHD: highly suspected for metastatic colorectal cancer).
A pulmonal embolism complicated early postoperative period.
We decided to start with chemotherapy and to finish diagnostic procedure after the first chemotherapeutic cycle. The patient received chemotherapy from 05-09/02.
In September 02 a tumor of sigmoid colon was found by colonoscopy. Because the patient was in good condition (KPS 100%, normal laboratory parameters) but with a high possibility of bowel-obstruction development, she underwent operation. Intraoperative finding was worse than expected: she had diffuse carcinomatosis of the peritoneum, and pelvis was completely blocked by the tumor mass.
Four weeks after surgery, she developed acute kidney insufficiency with high plasma levels of urea and creatinine. She was vomiting, and the X-rays of abdomen revealed ileus.
During her stay in the hospital, the patient was constantly using nasogastric tube. Left nephrostomy was performed because of kidney insufficiency. She felt high level of discomfort because of ileus, emesis, nasogatric tube, and pain (visual analog scale 4-5). In the terminal stadium of the malignant disease, chemotherapy was not indicated.
Our recommendations (anesthesiologist, oncologist, two gastroenterologists) were: the "best supportive care" only (infusions, nasogastric tube, pain therapy, antiemetics, and terminal sedation for 20-22 hours per day). The patient agreed with us, and for two days she underwent sedation (20 hours per day), but when we wanted to discharge her from the hospital, upon her wish, the family refused, rejected our recommendations and transferred her to another clinic. During her stay in the other clinic she underwent radiotherapy for peritoneal carcinomatosis (without any result). She was conscious the whole time (without any sedation), constantly with a nasogastric tube, suffering from pains and emesis. She died three and a half months after her transfer to the other clinic.
She was dysthanased for at least 4 months.

Concluding Remarks

The public opinion on one side, and medical professionals on the other, still approach the problem of dysthanasia with great caution. The reasons for such caution could be widely discussed. One of them is surely the fact that the problem of dysthanasia has not until recently been introduced into theory of medical law. This is witnessed through the mentioned *Recommendation No. 1418* by the Council of Europe (July 1999) (31), as well as through the following medical-legal documents, all of recent date: *Opinion on Ethical Aspects of Health-care in the End of Life* by the National Ethics Committee for Life Sciences (June 1995) (32),

Principles of the German Medical Association Concerning Terminal Medical Care by the German Medical Association (September 1998) (33), and *Opinion No. 063: End of Life, Ending Life, Euthanasia* by the National Consultative Ethics Committee for Health and Life Sciences - France (January 2000) (34).

Taking all this into account, there is, obviously, need to start a qualified discussion on dysthanasia, especially among the concerned medical professionals. Such a discussion may result in more precise suggestions for the legal formalization of this cardinal medical and bioethical problem.

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