Dealing with euthanasia requests: the insertion of palliative filter

Leo Pessini

Leo Pessini
Doctor in Moral Theology, integrates the Technical Commission on Terminality of Life and Palliative Care of the Federal Council of Medicine (CFM). Professor in the graduation program, masters' and doctors' degree in Bioethics from the *Centro Universitário Sao Camilo*, Sao Paulo, Brazil

Abstract This article discusses ethical issues related to the end of human life, presenting data from the Netherland and Belgium, countries that have specific legislation and public policies related to euthanasia practice. It highlights, particularly, Belgium experience regarding the introduction within the health system of the palliative filter procedure in face of euthanasia requests from competent patients who are in their final stage of life. It concludes by indicating that, despite persistence of the so-called 'casus perplexus', that is, of not giving up on euthanasia request, the proposal of palliative care becomes irrelevant and uncalled for in many of these requests.

Key words: Euthanasia. Palliative Care. Right to die.

The moment the Brazilian medicine launches it new Code of Medical Ethics (CEM)[1], on April 13, 2010 we considered appropriate to propose some reflections based on the experience of other countries, particularly Belgium and The Netherlands, dealing with polemical ethical issues on end of life. The new CEM predicts a differentiated ethical approach with patients in the final stage of life, to prevent the practice of dysthanasia and enhance palliative care.

At the Federal Council of Medicine (CFM), the Technical Chamber on End of Life and Palliative Care, which acts since 2005, has rendered important service in the context of the Brazilian medicine in terms of promoting professional ethical education. The highlight of this performance, without doubt, was the elaboration of Resolution 1805/06 of the CFM, still *sub judice* [2] Without it, whose publication has generated extensive debate in the Brazilian society on ethical issues linked to the end of human life (orthotanasia, dysthanasia, euthanasia and palliative care) the updates related to ethical decisions certainly would not have been approved in the new CEM regarding the end of life - that medical organizations from other countries have already incorporated in their assistance in the field of health.

To illustrate this assertion on how the new EMC addresses the ethical issues regarding terminality of life, we emphasize some principles, articles and paragraphs in the code that strive to preserve the indispensable respect and care. Principle XXII , for example, notes: *In irreversible and terminal clinical situations, the physician will avoid the performance of unnecessary diagnostic and therapeutic procedures and will provide to the patients under his attention all appropriate palliative care.* Art. 41 forbids the physician *to shorten the patient's life, even at his request or at the request of his legal representative*. Its sole paragraph indicates that in the cases of *incurable and terminal disease , the physician shall provide all palliative care available without undertaking unnecessary diagnostic or therapeutic or recalcitrant actions , always taking into consideration the express will of the patient or, in his impossibility, of his legal representative.*[1]

Finally, through the new Code of Medical Ethics, Brazilian medicine breaks the silence of the cultural denial of death and enters the 21st century by accepting the principle of human finitude. In the above code, of 1988, considered advanced for its time, the dimension of human finitude is not even mentioned among the nineteen principles listed, but we were experiencing a remarkable cultural moment of denial of death.

In 2002, The Netherlands and Belgium were the first countries to legalize euthanasia in the context of health care, on very similar legal provisions . The Netherlands had an institutionalized practice which, although not legal, was tolerant in relation to physicians who practiced euthanasia for at least a decade before the legalization. Also in Belgium these discussions echoed significantly. An interesting article entitled *The development of palliative care and the legalization of euthanasia: antagonism or synergy*?, published in the British Medical Journal [3], describes how these two areas of health care, deeply polemic from the ethical point of view, grew side by side with mutual benefits in that country. The authors show that although both procedures - palliative care and legalized euthanasia - are based on medical and ethical values, such as patient's autonomy, the beneficence of the caregivers and the non-maleficence, are often viewed as antagonistic causes.

The popular perception, for example, is that the cause of palliative care refers to the scope of the most religiously motivated persons and that the defense of euthanasia, in contrast, would be an area reserved for atheists or agnostics. The European Association for Palliative Care expressed concern to that effect, warning that with the legalization of euthanasia in The Netherlands and Belgium in 2002, the *slippery slope* would begin resulting in damages to vulnerable patients, such as the elderly and people with special needs, which would impede the palliative development with euthanasia as an alternative.

However, data from those countries, after the legalization of euthanasia, seems not to confirm this reality. Research conducted in Belgium regarding decisions that curtail the life of patients at the end of life, including euthanasia or medically assisted suicide, show no correlation with the low utilization of palliative care and that such decisions often occur in the context of multidisciplinary care health [4.5]. These findings allow to assume that the reflection on terminality of life encompasses aspects directly related to palliative care to the patient, and is not restricted to shortening of life, as if can be seen below.

This article, after presenting the situation of the legislation on euthanasia in the so-called "Netherlands", Holland and Belgium, has as its fundamental objective the presentation of the Belgian experience on the procedure of the palliative filter against requests for euthanasia by competent patients and at the final stage of life. Before presenting the framework of the legal context and of the public policies of Belgium and The Netherlands on euthanasia, it is suggested that, to know the specificity of the legislation in those countries it is recommended the reading of the work *Current problems of bioethics*, by Pessini Barchifontaine [6], in which these laws are fully reproduced, in the section of attachments This is the first work on bioethics in public health published in Brazil.

Current situation of the euthanasia practice in The Netherlands

Article *End-of-life practices in the Netherlands under the euthanasia act* [7], published by Agnes van der Heide and colleagues in 2007 *The New England Journal of Medicine*, brings data on end of life practices in The Netherlands. Shows that in 2005 from the total deaths occurred in the country, 1.7% resulted from euthanasia and 0.1% of medically assisted suicide. Interestingly, these percentages are significantly lower than those recorded in 2001, when 2.6% of all deaths were the result of the practice of euthanasia and 0.2% of medically assisted suicide. Of all the deaths, 0.4% resulted from the end of life without an explicit request by the patient.

The deep and continuous sedation was used in conjunction with a probable expediting of the death in 7.1% of all deaths in 2005 a percentage significantly higher than the 5.6% in 2001. In 73.9% of all cases of euthanasia or assisted suicide In 2005, life was ended using neuromuscular relaxants or barbiturates. Opioids were used in 16.2% cases and 80.2% of all cases of euthanasia or assisted suicide were recorded.

In The Netherlands, the number of cases of euthanasia and assisted suicide in 2005 totaled 2,297 and 113, respectively, totaling 2410 cases. Review committees evaluated 1933 of them, which corresponds to 80.2%. In 28 cases the physicians were asked about the reasons for not registering the practice of euthanasia in the records and in 76.1% of them answered that did not consider their acts as abbreviating life. Other reasons alleged were that the physicians had doubts if the careful criteria for the practices were followed (9.7%) or if the professional considered the procedures adopted at the end of life as a private agreement between the physician and patient (6.65). When asked about the choice of the most appropriate term for cases classified as euthanasia or assisted suicide, 76.2% of physicians have chosen euthanasia, assisted suicide or ending life. Practices of end of life in the remaining cases were named as *symptoms relief or palliative or terminal sedation* [7].

Belgium Legislation

Some definitions contained in the Belgium legislation on euthanasia, promulgated on September 22, 2002, enable us to better understand what is, in essence, the proposal for the filter implementation of palliative care upon requests for euthanasia. As to the definition of euthanasia, art. 2 specifies that *for the purposes of this law, 'Euthanasia' is defined as the act performed by third parties who deliberately put an end to life of a person at the request of this person*. Art. 3, section 1, defines the conditions for

performing euthanasia, specifying that *the physician who performs euthanasia is not practicing an illegal act if he is satisfied that*:

- The patient is an adult or emancipated minor and is legally competent anc conscious at the moment of making the request;
- The request is made voluntarily and weighted and reaffirmed, and is not the result of external pressure ;
- The patient is in a hopeless medical condition and complains of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident;
- He has respected the conditions and procedures as provided by this law.

Section 2 contains a description of well defined conditions of the requirements to be respected by the physician who practices euthanasia. This should in the first place and in all cases:

1. *Informing the patient about his health condition and life expectancy, discuss with the patient his request for euthanasia and the possible therapeutic and palliative courses of action that may still be considered, as well as the availability and consequences of palliative care. Together with the patient, the physician must come to the belief that there is no other reasonable alternative to the patient's situation and that the patient's request is completely voluntary;*
2. *Having given the persistent nature of physical or mental suffering of the patient as well as his reiterated desire. With this goal, the physician* should perform various interviews with patient, at a reasonable interval, taking into account the evolution of the patient's condition;
3. *Consult another physician about the serious and incurable character of the disorder, specifying the reason for the consultation. The physician consulted should review the medical record, examine the patient and must be certain of the patient's constant and unbearable physical or mental suffering that cannot be alleviated. After that, he should write a report about what his findings. The consulted physician must be independent of both the patient as the physician in charge of treatment, as well as competent regarding the pathological condition of the patient. The attending physician shall inform the patient about the results of that consultation;*
4. *If a team is involved, the attending physician responsible for the treatment shall discuss the patient's request with the team or with some of its members;*
5. *If the patient so wishes, the attending physician should discuss the request of the patient with his relatives, appointed by the patient;*
6. *Be certain that the patient has had the opportunity to discuss his request with them.*

Palliative filter for the requests of euthanasia by competent patients at a terminal stage

The procedure of the palliative care filter is based on the experience of the Belgian / Flemish Federation of Palliative Care. This pluralistic organization has performed a very active role in that country, in the sense that health services provide palliative care for all who need them and defends the initiative of including the palliative filter in the Belgian law on euthanasia.

The procedure of the palliative filter comes from the idea that one should do whatever is possible to support and assist the competent patient who in a final stage of life and asks for euthanasia. This support should be extended to their families. The purpose is that such an active and integral approach of palliative care may make it irrelevant in many cases, the own request for euthanasia, allowing the patient to die without the shortening of life.

The purpose of the filter of the palliative care is to ensure that all health professionals (physicians, nurses, experts in palliative care) talk about the request of euthanasia and the alternatives of palliative care. Therefore, care to a patient requesting for euthanasia must include the consultation with a team specialized in palliative care, aiming to analyze his real needs.

The question of pain and suffering is one of the challenges always present and the proposition of relief therapies becomes an ethical imperative . Thus, it is necessary to: a) provide tor patients in a final stage all means of relief and control of distressing symptoms; b) recognize that patient care and the relief of his suffering is not merely a medical issue, c) the care provided aims to physical, mental and spiritual wellbeing and, in this perspective, all professions have something specific to contribute in an effective and sensitive approach to the patient and his family.

For this reason, the physician must request, well early in the process, for the expertise of a palliative care team to discuss palliative possibilities and apply them to alleviate the suffering of the patient as much as possible. When it becomes clear that pain and distress cannot be adequately tackled using normal palliative methods, the technique of palliative sedation may be considered. The most frequent reasons to introduce the sedation are delirium, the dyspnea and pain, but also psychological symptoms can be taken into account.

When the shortening of life is requested

A request for euthanasia and, above all, a sign that the patient sends to elucidate his vision about being ill, in physical pain or the possibility of deterioration that can occur in a hopeless situation. Thus, each request must be open to discussion even if the patient is still medically away from the final stage. It is essential that the health professionals involved express their wish to listen to the patient requesting euthanasia while, at the same time, they must ensure that their decision for this option is based on a free, autonomous, free and informed choice. At this point the following questions should be made:

- Which motivation is on the basis of this request for euthanasia? Is this a request to really put an end to his life or is the patient begging for sensitive counseling in the last days or weeks of his life?
- Has the patient sufficient information (e.g. diagnosis and prognosis) that could support the request?
- Is the patient mentally competent when making the request?
- Has the patient discussed the request of euthanasia with others?
- Is the request volunteer? Is not there any question of any form of coercion or pressure?

When is it the case of providing a palliative procedure?

When considering the need to start the palliative procedure, it is essential to take into account several aspects which can be synthesized in the following steps:

a. Practical possibilities of palliative care are discussed to exhaustion by the physician responsible with the palliative care team of the institution

- What diagnosis and prognosis are given for the disease?
- What suggestions can be offered in terms of treatment of symptoms?
- What alternative treatments may still be offered to the patient?

b. The patient is fully informed by the physician that assists him about all aspects of his health situation and the existing possibilities of palliative care.

In these cases the patient will have the support of team of palliative care, as well as the clear opportunity to consult with this same team. Thus, he shall be informed about with who he can ask questions, what kind of care he can expect and what happens if he will no longer can decide on its own.

c. If the patient so wishes, the physician will discuss the request for euthanasia with friends and family he shall appoint

Under these circumstances it is important that the professional makes sure that the patient may answer the following questions:

- How does he understand the situation of his illness?
- What information does he have about the disease and the prognosis?
- What does he know about the possibilities of palliative care?
- What his relatives think about his request for euthanasia?
- How his relatives can receive support?

d. The attending physician will thoroughly discuss the request of euthanasia and the situation of the patient with the nursing staff.

Nurses must know that they have the right to follow their own conscience in relation to the request of euthanasia and may exercise their objection. The possible involvement with the practice of euthanasia can never go beyond nursing care; they can deal with the emotions that a request of euthanasia causes.

This procedure, just described, ensures that the possibility will be offered of good palliative care to all patients on a terminal stage that need it.

e. And if the request for euthanasia shall persist?

The experience of the palliative care teams shows that an active and full approach (including sedation) can, in many cases, make the solicitation for euthanasia irrelevant, allowing patients to die naturally, without shortening their lives.

The intention is that the palliative filter procedure works as a preventive measure in relation to requests for euthanasia and offers best assurance of adequate protection of the human person. The palliative sedation seems to work as an extremely valuable alternative to the practice of euthanasia, reducing to a minimum the so-called cases of necessity (casus perplexus). If in rare and exceptional cases, shall happen such states of need, the physician may face a dilemma of conscience. *In these extremely dramatic situations we respect the decision consciously taken by the physician* [8].

Observations in relation to the Belgium palliative filter

The ethical debate about euthanasia in Belgium and The Netherlands takes to realize that hereinafter the health professionals will always be more confronted with requests of this nature, as well as those aimed at alleviating pain and suffering. The procedure of the palliative filter used in Belgium, contributes to greater transparency in relation to development of practical guidelines written on medical decisions at the end of life. What is in tune with the world trend of the modern medicine : draft guidelines that orient physicians in limit and critical situations of health care . The need for such guidelines, besides being important and useful as a practical guide of intervention in critical health care , serve as the benchmark of quality in the care of health care.

The international recognition of need for practical guidelines aimed at how to deal with requests from patients for interventions at the end of their lives is recent. A study shows that 63% of hospitals Belgian / Flemish have ethical guidelines on euthanasia, which is facilitated by the fact that in those countries there is legislation on the subject. Christian hospitals implement palliative care and the procedure of the palliative filter is interesting in this aspect. In relation to the practice of euthanasia, they make what is called a *conscientious objection*, i.e., they do not practice it.

Although the procedure of the filter of palliative care is primarily oriented to the practice, its clinical application shows that the fields of medicine, ethics and law are interrelated. The health professionals will use it to improve the quality of care offered. It is observed that their decisions about end of life are not purely technical and medical but also ethical, since in its substance they deal with human values and require careful ethical discernment, such as human dignity, sense of life, quality of life - values that transcend clinical scientific discourse.

The approach used in the procedure of the filter of palliative care is *clinical bioethics* [6]. It focuses on the ethical aspects of factual clinical situation , with the attention to personal and professional expectations of the health professionals[8].

It is interesting to note that except in The Netherlands there are no studies about the experience of health professionals with practical clinical guidelines on the end of life care. The contribution of these professionals is of extreme importance because it focuses attention on important aspects of the content and objectives of the guidelines. This means that health institutions shall conceive palliative care as an active and integral approach to be adopted in patients in terminal stage. The request for the procedure of filter of palliative care is only credible if it is sufficiently developed and structured in the context of health care institutions, whether they are hospitals, clinics and / or ambulatory.

We need, however, to remember that the procedure of the filter of palliative care is not an answer to all clinical problems. One of the most difficult situations is that in which that patients requesting for euthanasia and refuse the use of any palliative measure. In these cases, there are clinical conditions and willingness to provide palliative care, refused by the patient. As previously mentioned, this is called as a *casus per-plexus*. Another aspect to be highlighted is that this procedure is specific only to patients who are competent and in final stage of life, and it cannot be applied to meet requests for euthanasia in patients for other reasons.

Final comments

It grows in Brazil the interest of medicine for the practice of palliative care. Some programs of palliative care are applied in public institutions - which number is increasing significantly - and we have already several publications on the subject. In the first case it is important to highlight the work of organizations like the National Academy of Palliative Care and the Brazilian Society of Palliative Care, which since 2004 and 1997, respectively, militate in the area by organizing conferences, symposiums and developing guidelines on acting. It is essential to indicate the contribution of reflection held in the framework of the Regional Council of Medicine of the State of Sao Paulo (Cremesp) which resulted in the publication on palliative care in September 2008 [9], as well as the own National Academy of Palliative Care which released a manual in May 2009.[5]

In large part, the movement toward the practice palliative care is driven by the development of technological medicine , which, recognizing its limits in terms of not achieving a cure in many cases, it ceases to invest therapeutically to not harm the dignity of people. Death is not a disease and should not be treated as such. By keeping this mentality, we will be willing to find a cure for death, which is impossible.

In parallel, the philosophy of palliative care shows that one can establish a healthier relationship with the reality of the end of life, overcoming the fears and taboos that present death always as an enemy, a failure or revelation of professional incompetence. In spite of the cultural differences, always present and which give also different solutions depending on the particular the context, it is important and healthy to know how other countries are responding to the fundamental human need of humanize care at the end of life in the dimension of their public policies. It is the case examined in this reflection on palliative care , which considered the reality of the two countries that have legalized euthanasia.

We are not sick people nor victims of death: it is healthy to be pilgrims in existence[10].But this does not mean that we can passively accept death as a consequence of disregard for life, due to violence, accidents and / or poverty. In this context, it is necessary, if not indispensable, to always cultivate a holy ethical indignation. This attitude in relation to contempt for life is the indelible mark of our humanity.

However, we must bear in mind that if we can be cured of a disease classified as mortal, we cannot abstain from our mortality. When we forget this fact, we end up falling into technolatry and absolutization of biological life. Influenced by these mental representations we foolishly seek for the cure to death and do not know what else to do with patients who come close to farewell to life. It is the therapeutic obstinacy

(dysthanasia) postponing the inevitable, that adds only more suffering to the sick, confusing quantity of life with quality of life.

A thought of Cicely Saunders, the great pioneer of the modern movement of *hospice*, well translates the essence of the philosophy of palliative care: *I care because you're you, I care until the last moment of your life and we will make everything within our power not only to help you to die peacefully, but also for you to live until the dying day* [11]. This inspired and compassionate reflection comes from newly-found wisdom on terminality of life, which includes acceptance and assimilation of human life care in the final goodbye.

Such reflection emerges as the Aristotelian way of virtue between the two opposed limits. On one hand, the deep conviction of not *intentionally shorten life* (euthanasia): on the other hand, the vision for *not prolonging the suffering and postpone death* (dysthanasia). Between the non abbreviation and the non extension is *you will love him* with his pains and rewards

It is a difficult challenge to learn to love the patient in the final stage of life without requiring return, with the gratuity with which we love a baby, in a social context in which everything is measured by merit! However, before such a mission we should not forget that human suffering only becomes intolerable when nobody cares for it. With the same zeal with which we cared at birth, must also be cared to die. We cannot forget that the key to dying well is in good living

Resumo

Lidando com pedidos de eutanásia: a inserção do filtro paliativo

O presente artigo discute questões éticas relacionadas com o final da vida humana, apresentando dados da Holanda e Bélgica, países que possuem legislação específica e políticas públicas em relação à prática da eutanásia. Destaca, de forma especial, a experiência belga a respeito da introdução, no sistema de saúde, do procedimento do filtro paliativo frente a solicitações de eutanásia a partir de pacientes competentes e em fase final de vida. Conclui apontando que não obstante a persistência dos chamados *casus perplexus*, isto é, a não desistência da solicitação de eutanásia, a proposta de cuidados paliativos torna irrelevantes e desnecessárias muitas dessas solicitações.

Palavras-chave: Eutanásia. Cuidados paliativos. Direito a morrer.

Resumen

Tratando con pedidos de eutanasia: la inserción del filtro paliativo

El presente artículo discute cuestiones éticas relacionadas con el final de la vida humana, presentando datos de Holanda y Bélgica, países que poseen legislación específica y políticas públicas en relación a la práctica de la eutanasia. Destaca, de forma especial, la experiencia belga a respecto de la introducción, en el sistema de salud, del procedimiento del filtro paliativo frente a solicitudes de eutanasia a partir de pacientes competentes y en fase final de vida. Concluye apuntando que no obstante la persistencia de los llamados *casus perplexus*, o sea, el no desistir de la solicitud de eutanasia, la propuesta de cuidados paliativos torna irrelevantes e innecesarias muchas de esas solicitudes.

Palabras-clave: Eutanásia. Cuidados paliativos. Derecho a morir.

References

1. Conselho Federal de Medicina. Código de Ética Médica: Resoluçao CFM no 1.931, de 17 de setembro de 2010. Brasília: CFM; 2010.
2. Federal Council of Medicine. Resolution CFM no 1.805, of November 9, 2006 [internet]. On the terminal stage of serious and incurable diseases it is allowed to the physician to limit or suspend procedures and treatments that extend the life of the ill person, assuring him the required care to alleviate the symptoms that cause suffering, in the perspective of a full care, respecting the patient's will or that of his legal representative. Revista Bioética 2010; 18(3): 549 – 60 560. Resolution suspended by a decision from Honorable Judge Rocerto Luis Luchi Demo, in the records of Public Civil Action number 2007.34.00.014809-3, at the 14th Federal Court, brought by the Federal Prosecution Office [access March 20, 2010]. Available at http://www.portalmedico.org.br/resolucoes/ CFM/2006/1805_2006.htm.
3. Bernhelm J, Deschepper R, Distelmans W, Mullie A, Bilsen J, Deliens L. Development of palliative care and legalization of euthanasia: antagonism or synergy? BMJ 2008 Apr;336(18):864-7.
4. Van Den Block L. Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium. BMJ 2009;339:b2772.
5. Academia Nacional de Cuidados Paliativos. Manual de cuidados paliativos. Sao Paulo: ANCP; 2009. 320P.
6. Pessini L, Barchifontaine CP. Problemas atuais de bioética. 9a ed. Sao Paulo: Loyola; 2010. p. 512.
7. Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJM, Wolf JEH et al. End-of-life practices in the Netherlands under the euthanasia act. Special Article. N Engl J Med 2007;356(19):1957-65.
8. Schotsmans P, Gastman C. How to deal with euthanasia requests: a palliative filter procedure. Camb Q Helthc Ethics 2009;18(4):425.
9. Oliveira RA, coordenador. Cuidado paliativo. Sao Paulo: Cremesp; 2008. (Cadernos do Cremesp).
10. Pessini L, Bertachini L. Humanizaçao e cuidados paliativos. 4a ed. Sao Paulo: Loyola; 2009.
11. Saunders C. Into the valley of shadow of death: a personal therapeutic journey. BMJ 1996 Dec;313:1599-601.

Received: 3.26.2010 Approved: 6.17.2010 Final approval: 6.24.2010

Contact

Leo Pessini - *pessini@saocamilo-sp.br*

Centro Universitário Sao Camilo - Reitoria. Rua Raul Pompéia, 144 CEP 05025-010. Sao Paulo/SP, Brazil.