

End of Life Pedagogy and Empathetic Guidance

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Abstract

The scientific progress has recently provoked profound physical and conceptual changes related to the end of life (EOL), and it has been necessary an intense debate about EOL and euthanasia. It is significant to define death as the absence of life qualities and not as a physical end. Hence, the end stage of our life is a crucial and meaningful moment. For this reason, it is essential to try to integrate the purely technical perspective with an ethic of guidance, which allows patients to live in dignity their death. For this reason, it urges to engage a continue and deep educational and experiential co-construction on the end of life, aware of its precariousness.

Keywords: Human dignity; end of life decisions; empathy; caring; education.

1. Introduction

The theme of death has crossed all the ages and a wide variety of context. Death seems like the last path of freedom in many historical characters in literature and theatre. The end is pursued by love, justice, regret, loyalty, contrasts to not shared social condition agents and life coherence. According to Seneca «*mors dolorum omnium exsolutio est*». Heidegger defined the death as «<the possibility of the pure and straightforward inability obeying there>>. A person is precisely a human being "destined to die". But people perceive it through a not experimental knowledge: the subject always experiences the death of the other without thinking on its own and what is noticeable is just the phenomenon of dying. Epicuro affirmed:

When we are, death has not come; when death is, we are not. Therefore it is for the living and the dead because it is not in those and these are no longer.

Seneca accuses of foolishness those mourning their loved ones:

Can someone complain if they knew it should happen? ... Who may sorrow of something when they know it is inevitable? ... Nothing is certain but death. However, everybody complains of this, which is the only not to mislead anyone.

Kierkegaard writes "death is Master of seriousness, but its serious training can be recognised by the fact it leaves the individuals free to seek themselves and then teach them the seriousness". (Kierkegaard, 1999, p. 42). This reflection of death assumes a pedagogical value: thinking the end gives the right impulse to live.

For the majority of people, death is an event you try to escape, living the present frantically by projecting into the future. In the West, death is a taboo more than anywhere else in the world because to summon it means showing the non-sense of whatever West has built. Death separates from the meaning of the person, and it is refused since inappropriate and dying has been extremely medicalised.

Our modern mentality has difficulty accepting the death, even at the price of enduring medically unnecessary procedures, aggressive therapies in contexts where the patient cannot be considered in their dignity of a dying person. The development of biotechnology necessitates to acquire awareness and knowledge of living and at the same time of dying. Biologically, death is the inability and the irreversibility of the body to maintain autonomously its organic

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functional nature, which doctors must declare with criteria accepted by the scientific community. However, healthcare professionals have to recover more than to take care of patients.

Recently it has developed a new sensibility towards the final stage of life. The focus has turned from the issue more concrete of death to the theme of death and to the willingness increasingly common to take effective decisions and not to delegate our end passively neither to doctors nor families. The living will try to express a mind of its own on death and how to die, without leaving it subject to the will of others.

While human beings try to identify the sense of death, they confirm the claim of the right of natural death, where nature does not mean just a demise due to the old age.

2. Real death and clinical death

Death has always been considered a point-like moment, a final breath, immediate border of transition from life to a state of non-life. Scientific progress, however, has recently provoked physical and conceptual profound changes relating to the conditions of the stage of the end of life (EOL). Death is not a point-like moment but a relatively long period that is complicated by several questions, possible choices, social interventions and legal denials, religious interferences and assertions of the right to die or to life dignity which reaffirm the complexity of current existence relating to EOL.

Hence, today it seems inevitable to open a deep and continue debate on crucial subjects as the concept of death, the moment of the end of life, endured or chosen with active actions or passive of euthanasia, physician-assisted suicide (PAS).

The time of transition has been increasing due to scientific knowledge and technologies which have split the real moments of dying. Strangely, the opportunity to do organs transplant and their request have complicated the bureaucratic availability, linked to the necessity to clarify who can be defined dead. The definition of death is essential for the removal of organs from the corpses and parental consent if the subject has left no indications in this regard.

To pull the plug, not conceptually but factually, belongs to that dead condition where all the brain functions (breathing, blood circulation, pulse and heart rate and involuntary motility) have ceased. In this case, the electronic device attached to the patient regulate those functions and give the appearance of life. On the contrary, other issues over which there is a semantic confusion need a clarification. The absence of electrical activity detectable with EEG, the flatline EEG, is not sufficient to declare death.

The paleoencephalon by itself may continue to carry out its functions through the autonomous nervous system enabling to survive (breathing, cardiac activity with passive supply) without any cognitive and relational activity. In this condition, it is even possible to survive for some decades. In such cases, we are talking about suspending feeding and hydration: the patient dies (is allowed to die) by starvation albeit adequately sedated.

3. Death: a complex system

The lack of unambiguous criteria on death involves not only dead people or the possible ones but also those that, in life, would wish to die but do not have access to it. In the unforgettable "L'armata Brancaleone" by Monicelli, the characters are essential, and Death is sure of its facts:

I am your Death!

Have not you called me? Get ready to die! How? Right now?

What are you waiting for? I am in there. You are in there ...

Many other characters, real or virtual, are available to decide on EOL and prevent you from make a personal point on when and how to end your life. If the death includes the loss conceptually of life dignity, as a result, it should be possible to decide when interrupting an existence that 's worth living. Such as is allowed to accept or not possible therapies through the informed consent document, it would be possible to accept or refuse to continue to survive a decent life. Unlike the informed consent, the living will consent in writing and signed in full consciousness, without a legal validation (it has been talking for ages in terms of legislation) is not applied.

The first obstacle is the definition of the loss of life quality, and even worse, the delimitation would define the loss itself. Starting from Kant's concept of dignity as unparalleled good and then priceless, it would be easy to view, but it is hard the concretisation. Dignity as bioethics is different from the international law definition or private or criminal law, or how a clinician or a familiar may conceive it. It is even harder placing it in the diverse meanings of therapy, determination, palliation and euthanasia. A measurement of the sense of dignity has also been suggested (Chochinov, 2004). Our laws do not include the possibility to give up life both on your own and to consent for necessary help.

Existential issues, spiritual, psycho-social, health matters and not last the extraordinary progress of medical technologies have resulted in death not being a natural moment but a period of different length, deprived of its emotional meaning, of its intimate awareness, of its dignity.

Death such as life has entered in the field of complex systems and then it should be faced and managed with the methodology of thought complexity, which considers the many interferences of causes and effects.

4. Social health background

The bioethical debate on EOL has been polarised between topics related to the sanctity of life and the necessity to ensure the EOL quality (Byock, 2009). In both cases, the issue revolves around the relevance and moral legitimacy of the individual decision on the end of life, in search of a kind and dignified death. The situation has been seen under a simple conceptual system. Choices related to EOL always involve others who may promote or proceed against actions that aim the interruption of living (Shaw, 2009).

The discussion is focused on a dichotomic position, for or against, and exacerbated from the deep contrast between lay and religious people who would not accept any request of euthanasia (Schotsmans, Gastmans, 2009). Doctors, who should be the most involved in the decision and operational support processes, show great reservation on this topic (Ritter, et al 2009). The subject seems to consider two crucial aspects: the legal issue and the implementation.

Oregon is the only American country with legislation, the Oregon Death with Dignity Act, which allows dying patients to receive medical support (Ganzini et al 2009). In Europe, currently in most of the countries if a doctor helps a patient would be accused of intentional murder. Holland was the first country in the world to approve the law to legalise euthanasia and assisted suicide in April 2001. Not long after, on September 2002, the law entered into force also in Belgium where from the 13 of September 2014 euthanasia on minors is legal. In March 2009 is the time of Luxembourg where the law provides that if doctors do not respond to a request for euthanasia, they would not be legally punished and prosecuted.

In Switzerland, also suicide assistance is allowed if free from selfish motives. Other countries like Sweden, Germany, Spain and France admit passive euthanasia but not the active one (except in Germany where a specif law does not exist, and the active euthanasia is accepted just if the patient's will is clear).

Italian legislation has never faced the euthanasia issue directly. In the absence of any specific regulation on this, in our legal system, the active euthanasia and assisted suicide are prohibited according to Article 575 (crime of murder), Article 579 (crime of consensual homicide) and Article 580 (crime of incitement and suicide assistance) of the Criminal Law. Passive euthanasia is more complicated. According to Article 41 of Criminal Law: "not preventing an event that is required to hinder is equivalent to cause it." (Bricolo, 2005, p. 67). Many studies have shown that decisions and procedures, latent or apparent, vary from country to country: the place of death can make the difference (Cohen, 2007).

5. Palliative care and empathetic guidance

In recent years it is giving increased attention to death as regards the dignity of the dying person. For this reason, palliative care centres are raising whose aim is to care for those who are dying and their family, for pain relief and accompaniment on the journey towards a dignified death. Palliative cares are a patient right (Law n. 38/2010) and free for those suffering from the disease do not respond to any specific treatment. Their aim is not to accelerate or postpone the death but make sense and dignity to life till the end. Palliative cares do not deny the scientific technological medicine but re-evaluate global and multidisciplinary attention of the person. That system has done an extraordinary job of awareness-raising to point out that patients are first of all people and their suffering is global, it concerns the physical, emotional and spiritual appearance. Care humanisation includes engagement from cultural and social fronts to project and training ones.

"It consists of start talking about death and especially facing the final stage of life, questioning ourselves on the meaning of the time for dying, how to live with dignity, with adequate support on a physical, psychological and spiritual levels." (Turollo, 2006, p. 100). Marie De Hennezel, a French psychologist and psychoanalyst, used to work in the palliative care unit at University Hospital in Paris and has been asked by the Health Ministry to spread the profound values of last stages of life. In her famous "La Mort intime", the author writes: "If the disease is an enemy to fight, death is not anymore." (De Hennezel, 1996, p.16-17). According to the writer, the time when death is close is not characterised exclusively by sorrow and pain, but it is a significant moment when the patients offer depth and strength moments and give interior richness to who they are with them.

De Hennezel writes: "When nothing can be done anymore, however, you may still love and be loved and many moribunds, when they die, they left this heartbreaking message: do not ignore living, do not ignore loving". (De Hennezel, 1996, p.16-17). Adopting "an empathetic attitude towards patients" is a care professionals matter. Edith Stein defined empathy as a 'sentient act', a full of life moment with which you enter in the other's experience. Empathetic guidance focuses on the patients' needs and not on the sick body, on the desires allowing them to express their feelings (Viafora, 1996). At the end of life guidance, being together with the dying person also silent gives a profound value to human relationship and allows the patients to live with dignity their time. The most significant benefit is to give them back their dignity as human beings.

6. Comments

In the socio-educational scenery, training to death is not simple. Without any doubt, it is necessary to treat the topic to ensure that human beings may learn to deal with this experience in the best conditions, psychological and social.

According to Garcia and Aura (2010) "death owns an extraordinary educational potential". For this reason, it should be necessary to develop a death pedagogy not to eliminate sorrow and fear that characterised it but to substitute taboos which surround and paralyse the most for what it provokes its evocation and reality. An education to death, a pedagogy to life, should start since childhood as something natural. Why do you educate to sexuality and not to death? If death, as well as sex, participate in life, why do you keep out death without discussing pedagogy of death? The education to die is based on believing that to avoid death but consider it part of life, you may change the Western culture procedures to reach the best conditions as a result of educational efforts. As Husserl said, "losing the other would lead losing oneself". The phenomenological performance is neither objectivist nor subjectivist but relationist (Bertolini, 2006). Your way to be in the world as embodied existence should be an opening to death (Bertolini, 2001). Life is transitory, a mortal existence from the beginning. You strive intentionally to ignore the grave, you deny it continually into an effort to escape it.

You ugly it up deforming the image, you insult it and avoid to call with its name, making different from the Self, you objectify in unacceptable positivism so you can exorcise it. But necessarily you should connect with it to understand our fragile life and to know the ego. Strangely, death is rejected by everybody, and you do not have any relation with it, no dialogues to prepare yourself to the longest journey. On the contrary, in some distress moments, it is a necessary law to clarify something that should belong to you. Consequently, you need to start an urgent and profound educational action, a continuing experiential effort for a co-creation of meanings of the end of life, aware of insecurity. You will train educators to create a dialogue where the relationship among protagonists is entirely linear. There will be time to mention de Montaigne: "...judging other's life, I always look at the way it happens the end, and, thinking of mine, I hope it will happen well, that is quietly and without noise".

To be able to give a sense to your life till the end, without reducing the existence to a simple wait for the inevitable lesson is an important lesson which the French philosopher Paul Ricoeur masterfully explains: «[...] nobody is moribund when is going to die, he is alive, and there is a moment, facing death when its tongue and limits and codifications are deleted to let to express something significant which is maybe to the base of experience. Life opposite death take capitalises the L, and this is the courage to live until death.» (Ricoeur, 2008, p.7-8).

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