In search of a Good Death

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ABSTRACT

Death has always implied confusion, so accompanying this end-of-life process entails a highexistential commitment. If we add to this difficult task the hospital or legal constraints suffered bypatients in their agony, we are facing a terrifying death, very far from a departure that can be considered a loving one. As we know, the word "clinical" refers to the practice of caring for the patient very close to the bed, alleviating the pain of whom is about to leave; however, the "legal corset" of death is separating the doctor from the one who should receive all his attention and care, preventing him from accompanying the pacient in his/her good dying. We should discuss and agree on a strategy that enriches the experience of the end of life, so that patients could choose the way to leave. It is of incalculable value to awaken compassion on this important issue that has concerned human since the beggining of civilization. It would be very fruitful if we take advantage of the enormous wisdom of ancient cultures that have humbly cared for life until the moment of death.

Key words: final process, awakening, law, compassion, good dying.

Death and dying have moved from a family and community setting to primarily the domain of health systems. Futile or potentially inappropriate treatment can continue into the last hours of life. The roles of families and communities have receded as death and dying have become unfamiliar and skills, traditions, and knowledge are lost.
Lancet[1]

Birth and death, dawn and dusk, are the most promising instants of the vital process (...) they have a great resemblance; they are the instants of maximum freedom (...)
Maria Zambrano[2]

PRELIMINARY CONSIDERATIONS ON THE END OF LIFE AND GOOD DYING

The final process of life is, undoubtedly, one of the central issues that unnerve human beings. This essay proposes a phenomenological reflection by giving space to different voices that reveal an approach to the good death. How we live and die has been a pressing problem from the dawn of time. The concern about what to do with the sick person when we believe that there is no possible alternative keeps repeating itself, even though we are immersed in an age when we have the most relevant knowledge in history. The Latin adjective "*infirmus*" gives rise to the Spanish noun "*enfermo*" (sick), which etymologically means "he who is not firm" and who seeks to stand up again not only physically but also with the necessary conviction to start his departure with dignity.

Anthropologist Arturo Sala[3] states that death can be viewed from three perspectives: as a social consequence, that is, death caused by accident, crime, or suicide; death

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as a natural process, natural cessation, or terminal illness; and finally, death as a cultural construction, which is the construction-deconstruction of effects of meaning and contents of consciousness around dying. As Sala argues, we try to recover death itself and not have meaningless death (pp. 64-5).

When the disease cannot be cured, does the patient have the right to decide whether or not to continue with his/her life? There is a debate about this sensitive decision, which aims to define whether or not it is an extension of the fundamental right to live with dignity. Just as there is no right to be born, to live or to die, because it is framed in the synderesis or indeterminate habit of the first moral principles, formulable in the terms "bonum est faciendum; malum est vitandum" ("good must be done, and evil must be avoided"), every action demands dignity in its development. The law exists only by the existence of natural facts. In any case, the law appears when the "right of the subject" is present, as Kelsen states 4 (p. 252). Every being has the right to be allowed to " be being"; life without dignity is not worth living.

However, it is still difficult to arrive at a holistic definition of legal and good death, some of which may include palliative care, readjustment of assistance measures, euthanasia, medically assisted suicide, or the refusal of established treatment.

CULTURAL, PHILOSOPHICAL, AND RELIGIOUS ASPECTS

If we look at the historical evidence, there have indeed been different legislations on the forms and legalities of death. Each culture defines this concept differently, according to its customs and beliefs.

In the Japanese culture, for example, there is the seppuku, through the harakiri technique, a samurai suicide ritual related to the honor of the person, which is accepted as a good death, not associated with illness. Although it is no longer a common form of death, it has become deeply rooted in symbolic representations and, due to its history and cultural impact, still commands enormous respect for those who choose this procedure to end their lives. People in Japan value this decision made by those who try to meet death at the right time. In the face of such a vital instance, a clear state of mind defines its legitimacy.

In Argentine popular folklore, for example, the word "*despenamiento*" ("*despenar*" in Spanish means "take someone out of grief") was used to designate a dignified death. It was not viewed as a criminal act, nor classified as murder, but as an intervention aimed at ending the pain of a patient suffering, motivated not by cruelty but compassion.

According to Vivante[5], the archaeologist and historian Márquez Miranda, based on Argentine authors who gathered information on the subject, considered "*despenamiento*" (the act of taking someone out of grief) as "the most modern euthanasia and the most extreme primitivism." The *despenador* was an individual who would kill the wounded, sick, and dying to put an end to their suffering (p. 215). Over the years, the authorities warned citizens of the illegality of this practice, but interestingly, many people began to cover up the identity of the *despenador* in order to continue with the ritual (p. 216).

Hume[6], the Scottish naturalist who shook philosophy awake from its dogmatic slumber, claimed that suicide is not a sin since if both life and death are God's will when pain tortures and exceeds our desire to live, one has permission to depart (p.121-2).

Likewise, the German philosopher Ernest Bloch[7] argued that, in the face of the irremediable, when torment cannot be endured, no human being desires death as something good but as a channel for doing good so that this act becomes a sign of life (p. 391).

In the Buddhist tradition, there is a built-in concept: to live dying and to die living. There is no fear of what is to come; one is available for immanence, for a way of being and doing in the here and now, in interdependence with all things and all beings on the planet. The feeling of the sick person is respected; the important thing is to perceive that the mind is calm to make the transition in harmony, with complete presence. As Watts[8] says: "Only conventionally can life and death be separated from things; in reality, that which dies is the living" (p. 125).

Now, the main argument in favor of a good death rests on a departure without agony, a word that comes from the Greek αγωνία, which etymologically means struggle, in this case, without strength for combat. The unnecessary prolongation of life is detrimental to the dignity of the sick person. Every human being in a terminal stage should have a good death, with the limits set by his or her circumstance.

At the same time, a good death entails an essential work: to approach empathically through undivided attention and deep understanding that finds us sharing in, being part of that pain, helping the sick person to unlock the suffering and the uncertainty of contemplating the joy of what is left to live[3] (pp. 23-4).

LEGAL ASPECTS AND CURRENT DISCUSSIONS IN ARGENTINA

In this sense, anticipatory directives are an appropriate recognition of the patient's dignity since they become an effective means of determining in advance the medical treatment he or she is willing to receive in the event that, when the time comes, they are unable to express their wishes. The countries practicing the good death share a similar model associated with suffering beyond relief and a soon-to-be irreversible end of life[9].

In Argentina, just as there have been advances in the abortion law, it is necessary to favor the conditions to promote a serious and well-founded discussion aimed at modifying a law that accompanies the process of the good death. It is worth mentioning the enactment of Law 27678, which seeks to improve the quality of life of patients at risk of death, but, despite this effort, it is remarkable how Science and the State do not focus

on some stages of human life. More than a substantial legislative contribution, we have the responsibility of building a national program, a practical guide to working with those who are about to depart*. For this, it is necessary to have a thorough knowledge of the subject and then transmit precise information about what it means to go in search of a good death to trigger a collaborative social discussion and a referential and operational framework that allows for a standardized application, an imperative condition for the State to make the right decision. As long as this debate doesn't become part of the public agenda, we are far from reaching our objective**. Likewise, in the medical practice of a good death, a palliative care policy should be contemplated to protect the transition to the end of life in the best possible way. The palliative care model must include a therapeutic approach to care, an essential affective-emotional support for pain management and increased comfort instead of empathic masking through medicalization. The patient and his family's quality of life requires the integration of all the physical, psychological, social, and spiritual aspects involved.

Recognition of a good death by the State does not merely constitute a humanitarian act but incorporates the patient's own decision. Along these lines, it would be inspiring if previous experiences were reflected in international treaties or the activity of specialized organizations.

As established in Article 28 of the Universal Declaration of Human Rights[10], expanded by Article 5, the State must guarantee conditions of a dignified life; however, if we consider the profound meaning of the text, we should ask ourselves: Is it possible to think of the good death as part of this right and, consequently, of the concert of life? If this premise is not fully endorsed, we would be validating an unethical approach to the fundamental act of the good death.

What can there be behind an attempt to prevent a sick person from ceasing to suffer if that were his or her will when medicine can no longer do anything, and that being is no longer social, the primary attribute of all humanity?

Unquestionably, several conditions feed the blindness that blocks the possibility of a good death. It is precisely this order of things that Sala[11] describes as being sustained by the perverse slogan: "I cannot even freely dispose of my body or my mind" (p. 183). In fact, Law 26529 sparked many controversies, a range polarized between rejection and acceptance without objections; others point out possible legal issues since –in its current wording– such a law hides the possibility of an interpretation that endorses suicide. Under such conditions, the law cannot consider the possibility of a good death. What is beyond doubt is the ambiguity of the information offered to the general public and the patient. So far, the legislation only allows the patient the option of leaving written advance directives on life support measures as the only tool that guarantees that his last will is honored.

In other words, the patient has to decide which choice he/she will make, if he/she wants to do it in solitude, accompanied by the family or nearby healthcare personnel. The experience of life is left behind when we are not, when we are tied down and prevented from going to the place we hope to reach according to our belief system. From this perspective, we approach the funnel of collaborative and compassionate action.

Approaching the good death

So what do we need to have a good death?: *compassion*. Its etymology - from the Latin *cumpassio*, a translation from the Greek word *sympátheia*, "to suffer with" - connects us with the highest expression of empathy. In the Buddhist tradition, "compassion" - in Sanskrit *Karunā*- means "to feel with the other" but not in the exclusive sense of having a compassionate feeling for another person or simply feeling something for the other, but with the other, empathysing, so as to connect with the other and with oneself.

As Wukmir[12] says, "the recipes of love and compassion are old, yet valid for all times. But the technique of their application is still embryonic (...) What is lacking is a good technique for their application" (p. 21). The profound sense of compassion was first noticed by Teresa of Avila[13], master in the experience of the good death, who used to recall how she managed to accompany her father's process in this way: "I had a hard job in his illness. I think I served him some of what he had gone through in mine. Even though I was very ill, I tried hard, and I was missing all the good and gifts, because in a being he made me, I had so much courage not to show him grief and to stay until he died as if I felt nothing, and my soul seemed to be tearing away when I saw his life end" (Book of Life, 7:14).

These days we express emotions emphatically, and death has acquired another value, perhaps one closer to the real one. Consciously re-appropriating this return can generate a relational movement, a form of collective compassion, which calls for a ritual of engagement with the suffering of the other.

However, at present, we are witnessing a vain and sterile confrontation between reasons that obstruct a genuine dialogical encounter. Deciding our end should be a fundamental and inalienable right, as important as education, security, or food. There is an urgent need for a public policy that focuses on solving and offering a compassionate alternative to the patient at the end of his or her life so that he or she is not locked in the deception of a natural evolution toward death.

It is evident that most States face increasing difficulties in satisfying the needs of their citizens, especially in

*It is commendable to mention the efforts made by different institutions and foundations such as Paliar, Movimiento Hospice Argentina, AAMyCP, and the palliative care area of Hospital Italiano, among others.

**The debate among legislators is currently underway. At least three bills can be named: "Alfonso Law," "Voluntary Interruption of Life," and the "Law of the Good Death." So far, none of them has gained the committee's approval.

matters related to the human problems inherent to the end of their existence. International law does not provide specific regulations on how one should die without pain and excessive therapeutic effort, nor does it offer guidance on ethical responsibility during the dying process.

The consensus among critics is that it is preferable to be alive despite the pain and that it is impossible to define or quantify its reality. They also accuse the countries that have legalized euthanasia of having turned it into an instrument of common indication that does not respect the gift of life. Another question arises: In what interstice is the life of a sick person who can no longer resist?

Hans Kelsen[4], an Austrian jurist and philosopher, explained the edges of this problem as follows: "If the moral norm orders us never to kill a man and the legal norm orders us to kill in war or to carry out a death sentence, we will have the power to choose which of them we will obey and which we will violate, but we will not have the power to undermine the validity of the norm we do not wish to obey. It remains valid because otherwise, we could not violate it" (pp. 252-3).

In conclusion, the Argentine State should debate in a cooperative and dialogic way the issue under discussion, seeking to culturally enrich the debate, generating a pathos, a matrix that produces and re-generates networks, creating a never-ending web of networks. Such would be a State that cares for the most valuable thing it has, its inhabitants, a State whose constitutional obligation to help people live with dignity demands that it commits itself to the possibility of a good death.

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