

## From inexorable death to chosen death

### De la muerte inexorable a la muerte escogida

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The opening of the first Colombian intensive care unit at the San Juan de Dios Hospital in Bogotá in the early 1970s was a significant step forward for the advancement of medicine in Colombia, and it highlighted the need to consider the appropriate use of technology in the medical field and critical care situations<sup>1</sup>. Subsequently, the arrival of the Pro-Right to Die Foundation in 1979 - initially named the Humanitarian Solidarity Foundation - introduced the first advance directive in the country, creating a space in society to reflect on the limits of medicine in end-of-life care<sup>2</sup>.

As in many other parts of the world, there was a concern about the dehumanization of dying. This meant that people were increasingly dying in the cold and controlled space of a hospital, far from their loved ones, and subjected to the dictates of highly technologized medicine that was becoming less and less aligned with the desires of the patients<sup>3,4</sup>.

For Jesuit priest Alfonso Llano Escobar<sup>5</sup>, one of the pioneers of bioethics in Colombia, the main bioethical issue in Colombia in the 1980s was the prolongation of patients' lives thanks to the power of medicine. He cited the increase in academic events dedicated to discussing this issue during that time. For Llano Escobar, it was evident that the enormous development of medical technology had made dying a problem in those times. The medicalization of life and death was advancing rapidly, related to the dehumanization experienced in healthcare institutions<sup>6</sup>.

The question then arose about how to avoid unnecessary suffering brought about by the prolongation of life in terminally ill patients due to unlimited use of technology and because doctors are often trained to exhaust all possibilities but not to think about when to stop or redirect their therapeutic efforts. This problem still exists more than 30 years after these reflections began in Colombia<sup>7</sup>.

Today, we know that an all-out battle against death is misguided, as death is an invincible enemy (even the universe, which appears infinite and eternal, has its numbered days, even if we must count them in eons). A more rational and potentially successful struggle is the one society and medicine can wage against suffering, pain, and loss of quality of life. The humanization of dying emerged alongside criticism of dysthanasia or therapeutic obstinacy, as it is also known. The discussion shifted towards patient rights, bioethics, respect for autonomy, and the appropriate use of limited resources in healthcare.

In the 1990s, a series of transformations also impacted how medical technology and end-of-life care were conceived. A significant sociopolitical and cultural transformation occurred in Colombia from a new political constitution in 1991. This constitution addressed fundamental rights for individuals and respect for personal autonomy, which meant reduced state interference in private matters.

The discourse on freedom of choice and the rise of personal autonomy as an ethical principle in society was a significant commitment of the new constitution and the result of new ideological winds blowing in the region. The wave of neoliberal ideology that arrived in Latin

<sup>1</sup> One question that arises is: what are today's "somas"?



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America from the 1980s onwards promoted, among other things, the idea that the individual is a kind of self-manager and that the State should be minimized<sup>8</sup>.

The rise of personal autonomy as a fundamental value in society, which has constitutional status in Colombia through Article 16 of the Political Constitution of 1991<sup>9</sup>, paved the way for individuals to assume decisions about their own lives fully. In the same decade, a healthcare system emerged that integrated discourses related to the market, supply, demand, autonomy, and free choice<sup>8</sup>. It is also the time when bioethics discourse gained strength in Colombia, which is not coincidental, as the principled and Anglo-Saxon bioethics that arrived in our country emphasized precisely the respect for autonomy and the ethical problems related to biotechnological development within a healthcare system that was being born<sup>8</sup>.

In this context, the Constitutional Court ruled in sentence C-239<sup>10</sup>, which divided the history of dying with dignity and euthanasia in Colombia into two. This ruling allowed euthanasia to be freely and autonomously requested by the patient and performed by a physician under certain conditions: terminal illness, intense suffering, or pain that is difficult to manage. According to Mendoza et al.<sup>11</sup>, “euthanasia is helping someone already dying to die, at their request, seeking an easy, peaceful, and painless death. The dilemma is not between life and death but in how one chooses to die. For those who do not have a terminal illness, the question is whether one’s life justifies being lived. They are not facing imminent death but desire to die” (p. 326).

This ruling has been controversial since it was pronounced<sup>4</sup>. However, although it is an endless debate, it is not futile to continue discussing the issue. Some matters and aspects can be nuanced, clarity can be achieved, and agreements can be reached. In the years following the C-239 ruling<sup>10</sup>, Colombia entered a kind of a legal gray area due to the ineffectiveness of the Congress of the Republic in regulating the matter. The presented Legislative initiatives failed, leaving individuals and institutions in Colombia without a clear framework to rely on.

Nevertheless, euthanasia seemed possible, but not within the confines of the healthcare system. The physician Gustavo Quintana, a sort of Dr. Kevorkian in the Colombian context, used to appear in the media claiming that he performed euthanasia, but he never faced criminal charges. At the same time, euthanasia remained taboo in healthcare institutions, and all requests to carry out this procedure were denied.

Without legislation from the Congress of the Republic, the Constitutional Court issued ruling T-970<sup>12</sup>, which ordered the Ministry of Health and Social Protection to establish guidelines for euthanasia requests. It was a jurisprudence case involving a woman whose healthcare entity had denied her request, which ruling was fulfilled with the issuance of Resolution 1216<sup>13</sup>, which recognized the autonomy of the terminally ill patient and their right to die with dignity, including the procedure of euthanasia if the patient so desired.

In parallel, the Congress of the Republic enacted Law 1733<sup>14</sup>, also known as the Consuelo Devis Saavedra Law, as a tribute to a woman in a coma for 14 years. This law establishes an obligation in Colombia to provide palliative care to those who require it. Her husband provided Consuelo Devis Saavedra’s care because the country did not have a regulatory framework for providing palliative care services and managing terminally ill patients or those with chronically debilitating diseases. Today, the proper provision of such services is mandatory, given that to the contrary, their absence could cause harm to individuals with terminal or chronic conditions and may represent a missed opportunity for the appropriate management of their health<sup>15</sup>.

However, it is necessary to acknowledge that, even when receiving quality medical care, including palliative care, and having adequate emotional support and basic material necessities of existence, some individuals may still insist on requesting their death when they are suffering from an incurable and debilitating illness, whether they are in a terminal state or not. This is when we talk about euthanasia and assisted suicide. In the first case, someone’s death is caused

to free them from unbearable and incurable pain or suffering, as defined by the individual. In the second case, the person causes their death, although they may receive assistance from others, just as Ramón Sampedro did in Spain in 1998, which case was portrayed in the film “The Sea Inside” directed by Amenábar<sup>16</sup>.

Later, with the Constitutional Court’s ruling T-540<sup>17</sup>, the right to access euthanasia for children and adolescents was recognized. This ruling assumed personal autonomy in a dynamic and progressive sense. The Ministry of Health and Social Protection issued Resolution 825<sup>18</sup> to “effectively enforce the right to die with dignity for children.” More recently, with ruling C-233<sup>19</sup>, a further step was taken by removing the criterion of terminality as a condition for accessing euthanasia. The Ministry issued a new resolution, 971<sup>20</sup>, which reorganized everything related to death with dignity and euthanasia, repealing Resolution 1216<sup>21</sup>. In its considerations, this resolution provides an excellent summary of the path taken on this matter in Colombia, from ruling C-239<sup>10</sup> of 1997 to the present day, and in its application, it provides clarity on the different concepts, procedures, steps, and processes involved.

One of the characteristics of this period that followed ruling T-970<sup>12</sup> was the emergence of faces that represent or reflect elements associated with the end of life, dying with dignity, and euthanasia in particular. Among these elements are suffering, waiting, pain, and resignation. However, simultaneously, the media paradoxically amplified other meanings through these faces: bravery, joy, decisiveness, and, of course, autonomy. The first face that became famous was Don Ovidio, who underwent the first euthanasia procedure considered legal in Colombia in 2015. Don Ovidio<sup>22</sup> was the father of the famous Colombian cartoonist Julio César González, better known as Matador.

In the prologue of the book “La eutanasia de Ovidio González”<sup>22</sup>, which compiled cartoons created by his son Julio César González, Matador, depicting the arduous path his father had to follow to obtain euthanasia from the healthcare system, Matador states: “[i]n my personal opinion, euthanasia has absolutely nothing to do with death. That is a misconception. The central focus of euthanasia is the rejection of pain and the indignity of human beings having to suffer unspeakably from a terminal illness” (p. 16).

Perhaps Matador is right. This debate about dying with dignity and euthanasia might not be about death after all. So, what is it about? If we carefully examine the way jurisprudential developments have unfolded (court rulings, legal interpretations from different ideological perspectives, debates on pros and cons in bioethics, among others), we could think that at a societal level, there has been a dynamic of insistence around obtaining the rights and guarantees sought by those who have chosen to die when they consider their lives, for health reasons, not worthy of living. I dare say there has been a furry unleashed, an intensified impulse, or frenzy to break down barriers in the face of the remaining obstacles that prevent people from accessing a dignified death according to their convictions, which sometimes includes euthanasia.

As stated by Mendoza *et al.*<sup>11</sup>, “[t]here are five relevant scenarios related to the concept of dying with dignity and clinical decision-making at the end of life: palliative care, living wills, limitation of therapeutic effort or therapeutic reorientation, palliative sedation, and euthanasia; the latter continues to generate the most controversy worldwide” (p. 326). For some, euthanasia is a way to die with dignity and can even be seen as a continuation of palliative care. However, there are indeed opposing positions. For example, Sanz *et al.*<sup>23</sup> stated that “[e]uthanasia does not replace palliative care. Nor does it complement it” (p. 47). For them, and many others, the solution is not to accept euthanasia but rather to have more faith in palliative care, which they believe “helps alleviate some of the problems of loss of autonomy, discouragement, or anhedonia that explain the low number of euthanasia or assisted suicide requests in countries with adequate development of these care practices”<sup>23</sup>.

Thus, the administrative, legal, and medical procedures seem to have been resolved, and there

is a certain clarity about how to proceed with this issue in Colombia. However, it is necessary to go beyond the prominent aspects of the debate and these developments. In a society that has made individual autonomy and freedom of choice a fundamental ethical principle, essentially making the individual an idol, one must question what else is functioning behind the scenes besides expanding space for individuals to be full moral agents in charge of their own lives.

Among the pending issues to be analyzed are the actual dimension of autonomy exercised by individuals who request euthanasia on the one hand and the extent to which patients receive timely and quality palliative care on the other hand. It is also important to consider how this ethical-legal dynamic reflects certain cultural and political transformations of our time related to economic, ideological, political, and power structures. I will briefly refer to these latter concerns.

The pro-right-to-die movement emerged in the mid-20th century as a response to the impact of technological and scientific advances in biological sciences and medicine on the dying process. This impact is also related to a transformation in how we perceive ourselves and approach life (self-understanding), the social relationships that are determined now more than ever by the exercise of individual autonomy than before, and how ideals of life are constructed through various discourses (people today prefer having pets over children, spending money on travel rather than saving, experiencing freedom in all possible ways).

The increasing focus on healthcare, in general, has led to the medicalization of life<sup>24</sup>, including the treatment of chronic and terminally ill patients; even dying has become medicalized. What was once considered inevitable and determined by fate, such as the tragic fate of our existence—death—is now subject to medical intervention. This has also meant that death has become less common in homes or other settings and increasingly occurs in hospitals<sup>25</sup>.

Contemporary society has gradually lost direct contact with death due to the intervention of hospitals and other institutions that have made death fade away. What we see now are catalogs and offers of funeral services, vigil, cremation, cemetery parks, and grief management; a portfolio of options for disposing of the deceased's body—a body whose material existence matters less in favor of a series of rituals dictated by new mechanisms of managing life and death. Alongside the biopolitics described by Foucault<sup>26</sup>, a particular type of power over living beings that emerged in the modern and capitalist world, especially over individuals and human populations, we also see the appearance of thanatopolitics or necropolitics, as a set of strategies for managing dying and death<sup>27</sup>.

In his studies on power in the social field, Foucault described various types or strategies that direct people's lives, encompassing not only their actions but also how they perceive themselves and relate to others, themselves, and their bodies<sup>8</sup>. Sovereign power stems from the authority that the king had to "let live or make die" (26), and today it is manifested through the various ways in which the state permits or restricts individuals' actions, either through laws or by force. There is biopower, which is exercised over people's bodies through disciplining<sup>28</sup> in institutions and social practices, or over populations through biopolitics, which includes, for example, all public health measures such as those experienced during the Covid-19 pandemic and all policies relating to the health and life of societies. Finally, there is governmentality, a type of power that no longer requires coercion or discipline. Now it is all about governing, and individuals need to be free. Freedom is not only a right or a highly valued good but also a strategy of governance<sup>8</sup>.

The movement for a dignified death and the right to euthanasia is part of this transformation in the way we experience and deal with death and dying in the contemporary world, and they are the result of new strategies of power and governance. In our time, individuals have come to believe they can choose the death they want, where they want, how they want, and with whom they want. And we continue to move forward on this path toward broader expressions of— -apparent—- freedom. In the case of Colombia, which has one of the most progressive legislations in the world regarding the right to die with dignity and euthanasia, a significant portion of society feels that a great achievement has been reached: respect for individuals' wishes.

It is proclaimed that the value of life is what each person assesses for themselves. Furthermore, the discussion about the meaning of life is overshadowed, in the realm of public discourse, by the question of whether the decision to die is one's own or imposed (by the State, family members, doctors, or any other actor other than oneself), whether my rights are respected or not.

The decriminalization of euthanasia and the struggle to ensure a dignified death has raised several issues. First, how we understand death and dying today has become liberal; it is no longer purely tragic, religious, or terrifying. Like many other matters, in contemporary liberal and plural societies, people wish to have control over their life plans, deciding how they want to live, and their plans for how to die. This cultural transformation runs parallel to a deep dissatisfaction in society with the callous, insufficient, and sometimes abusive manner in which healthcare is provided and the healthcare system operates about chronic and terminally ill patients. One of the major shortcomings in the education of healthcare professionals is that they are taught very little about how to care for this type of patient s<sup>6</sup>.

Secondly, it has become clear that the role of the State in this new stage of social life is no longer to treat its citizens as incapable individuals who need to be told what is good and what is wrong because they don't know. As suggested by Judge Carlos Gaviria Díaz from the Constitutional Court<sup>29</sup> in an international bioethics congress organized after the C-239 ruling<sup>10</sup>, citizens must take responsibility for their own lives, including their death. In a constitutional state, this is the ideal. Therefore, people should be respected in their decisions regarding their own life and body, including dying.

Thirdly, in the 25 years following the C-239 ruling of 1997<sup>10</sup>, a significant effect has occurred in Colombian society: people have become increasingly aware of their stance towards death and dying. It is worth emphasizing here that "dignified death" and "euthanasia" are not synonymous, as I have repeated in different forums<sup>2</sup>.

Similarly, fourthly, the impossibility of reaching a generalized ethical agreement on euthanasia or mercy killing through a judicial decision reveals other paths to address ethical problems that often lead to a deadlock, as frequently happens in bioethics. If certain ethical dilemmas or problems cannot be resolved, the law allows both sides to have their ethical positions respected within certain minimum standards that need to be established, for example, through a constitution. Thus, those who uphold the absolute sanctity of life are guaranteed the possibility to live according to their wishes until the end and to promote their ideas in society. At the same time, those who think differently, that life has the meaning each individual gives it, have the right to receive the necessary services from the State in a timely and high-quality manner. This is what has happened in Colombia and is something to be celebrated.

Fifthly, it has become clear that medical ethics cannot be understood merely as a rehashing of the principles expressed in the Hippocratic Oath<sup>(2)</sup>. When experts from around the world and different disciplines gathered in the late 1990s at the invitation of the Hastings Center in the United States to analyze the goals of contemporary medicine, it was deemed necessary to consider the characteristics of a highly scientific and technologized medicine, as well as emerging ethical and cultural values such as autonomy and justice<sup>30</sup>. According to Camps<sup>31</sup>, in his presentation of the book that compiles the conclusions of this meeting, "because medical science is now more powerful, we must seriously question whether it should do everything it can technically do, whether the goal of restoring health and avoiding death is not too simplistic or unrealistic anymore" (p. 5).

Among the conclusions of this meeting is the acceptance that, in market economies, medicine seems to be called upon to participate in satisfying individual desires. Today, medicine is not seen solely as a means to treat diseases (therapeutics), but also as a way to help individuals fulfill certain ideals, such as aesthetics. It is worth considering that the current insistence on the ability of each person to choose how and when to die also fits into this dynamic, which we could call the medicine of desire<sup>32</sup>.



There was also consensus that the enemy of medicine is not death per se. Instead, “[i]t is death at the wrong time (too soon in life), for the wrong reasons (when it can be medically prevented or treated at a reasonable cost), and death that reaches the patient in the wrong way (when it is prolonged unnecessarily or when the patient suffers unnecessarily without relief) that truly constitutes an enemy”<sup>30</sup>. However, thinking in this way requires moving away from dogmatic or simplistic positions.

Finally, it was recognized that it is impossible to settle the debate for or against euthanasia. For some, euthanasia and assisted suicide may be morally legitimate means to alleviate pain or suffering in extreme or terminal situations. However, for others, this intention, which may be a “perfectly reasonable in itself, does not morally justify the use of medical techniques with the direct aim and intention of causing a patient’s death, whether it is the physician who causes the death, or the physician merely provides the knowledge and medications necessary for the patient to commit suicide”<sup>30</sup>.

The expropriation of one’s death due to the limitless use of science and technology in the medical field or the imposition of particular beliefs in the social or political sphere constitutes the backdrop that gave rise to the movement for dignified death and euthanasia in today’s world. The invocation of human dignity and respect for personal autonomy are related to the emergence of this debate in the contemporary world, acknowledging that in a plural and liberal society, it is individuals who determine the value of their lives and, therefore, can also decide how their death will be. In many other areas, we have already recognized the authority of the individual: in determining life plans, accepting or refusing medical treatment, and so on.

According to Baum<sup>33</sup>, “the acceptance or rejection of euthanasia falls upon the individual whose health condition is serious and irreversible.” On the other hand, the permission or prohibition of euthanasia from a legal standpoint would be related to the public health policy that each state designs based on the incorporation or absence of a moral criterion of compassion towards human suffering” (p. 12). This means that it is necessary to distinguish between the levels of the discussion: the ethical level, which primarily concerns the individual (although, of course, society is always present), and the legal level, which reflects the type of social order that a country has chosen, which can be more or less democratic, inclusive, and respectful of diversity.

Following Baum<sup>33</sup>, from a bioethical and public debate perspective (in the Kantian tradition), there would be a “criterion of compassion [that] would support the right of every human being to freely choose their life plan, including the right not to suffer due to an irreversible and torturous illness.” In light of this, the State could not act paternalistically, treating its citizens as “incapable” or minors, nor could it allow “any human being to be treated as a means to an end (social, religious, economic, or otherwise),” as this would undermine human dignity and personal autonomy<sup>33</sup>.

However, the guarantee of a dignified death, that is, one that aligns with one’s values and perspective on life, cannot simply consist of allowing everyone to do as they please regarding the manner of their death. A sort of “à la carte” approach to dying is dangerous. For example, in many requests for euthanasia, what needs to be recognized is not the individual’s autonomy but rather their unmet healthcare needs, suffering from neglect, or loss of social connection<sup>8</sup>. It could happen that various social pathologies ultimately manifest in the existential despair of individuals and their consequent desire to live no longer. In such cases, if we provide euthanasia without addressing the underlying issues, there would be no triumph of personal autonomy to celebrate or any gain in respect for individuals’ rights. It would be a failure of society due to a myopic view of the problems afflicting its members or an uncritical adherence to the dictates of fashion or politically correct discourses.

It is also distressing to imagine a world where, in our attempt to eliminate the fear of death and insist that it is merely a part of life that should not affect us, we become alienated in other ways. This scenario is depicted in Aldous Huxley’s novel “Brave New World”<sup>34</sup>, which portrays a dystopian future world dominated by science and technology, as well as the subjugation of

individuals to an omnipotent, central, and totalitarian power (the “World State”). All of this is done in the name of the supposed complete happiness of the inhabitants of that world, which ultimately leads to a general numbing and a deplorable dehumanization of society.

In this happy world, where the slogan is “community, identity, and stability,” people no longer suffer thanks to physiological and psychological conditioning that leads them to view and feel death as something completely natural and devoid of emotions. To achieve this effect, there is also “soma,” a substance taken by all individuals in this society, which keeps them in a permanent state of collective daydreaming and constant sensory excitement through heightened eroticism, sensory cinema, and other strategies<sup>35</sup>.

In this world, there is the “Park Lane Hospital for the Dying,” where those who are scheduled to die go. Linda, a “savage” woman who has escaped from that dystopian and totalitarian society, and has lived on the Reservation, a place where individuals do not have access to soma and are not subjected to any conditioning, was hospitalized there because she would die. “...accompanied and with all modern comforts. Cheerful synthetic melodies filled the environment with life continuously. At the foot of the beds, in front of the dying occupants, there was a television that operated like an open tap, from morning till night.” When her son John, the Savage comes to visit her, the nurse explains to him, “We try to create a really pleasant atmosphere, something like a first-class hotel and a sensory cinema room...” (p. 399-405)<sup>34</sup>. It is not difficult to think that something similar is happening today in many of our hospitals and hospice care centers, which are in vogue.

As John watches his dying mother, he feels sadness, and his face transforms. The nurse becomes disturbed and startled because she is not accustomed to seeing expressions of pain in the face of death; no one suffers, not even in the presence of their dying mother. For the nurse, what John is experiencing is unacceptable and shameful (it is not difficult to see that in many hospitals, it seems as though expressing pain is forbidden). The children, who were visiting the Hospital for the Dying as part of their conditioning, are also affected by the spectacle presented by Linda’s old, fat appearance because, in this dystopian future, everyone remains vibrant and youthful until the end. Aldous Huxley’s depiction is not so much of a happy world but a world devoid of humanity.

Have we already begun to move toward that world?

How can we respect people’s wishes regarding dying without succumbing to mechanisms that only seek to manage life and death?

What does it mean to be truly autonomous and free?

What transformations still need to take place in the education of healthcare professionals and in the healthcare services provided so that individuals with chronic and debilitating illnesses, as well as those at the end of their lives, feel well cared for and respected?

## Conclusions

Human life encompasses both light and darkness. There is no happiness without sadness, no joy without pain. If we banish entirely suffering, we would also close the door to joy. It is not about embracing masochism or rejecting the benefits of science. Rather, it is the recognition that the fullness of human life lies in finding an appropriate balance amidst all that it brings.

Assuming one’s death is an act of responsibility. Respecting the various choices that this entails represents an ethical and moral duty for society. The right to approach one’s death in a way that reflects personal values and beliefs should be protected and guaranteed by law. The law cannot impose a specific understanding of a good life and a good death. It should ensure a broad framework for each individual to live fully following their values and beliefs while also establishing reasonable limitations to prevent excesses or exploitation.

Indeed, we cannot simply celebrate because we are now more autonomous, have more freedom, and live lives where the fulfillment of desires is paramount, even in the context of our deaths. It is necessary to carefully examine the broader implications of this debate and these “advancements,” such as in contemporary biopolitics and necropolitics, as well as the governance of individuals who believe themselves to be free even in deciding their deaths.

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