Revista Bioética
Print version ISSN 1983-8042 | On-line version ISSN 1983-8034

Rev. Bioét. vol.29 no.4 Brasília Oct./Dec. 2021

Vade mecum about dying and death

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Abstract

Considering the impact of death on multiple aspects of human collectivity, this article reflects on how different cultures, at different times, related to this theme, seeking to interpret the various meanings associated with finitude. Therefore, the study starts with a literature review of a qualitative approach. It found that civilizations that have succeeded each other over the centuries have in common a number of barriers to understanding and accepting death. And, despite new sociocultural paradigms, freedom of expression and all the technological evolution that characterize contemporary society, the demystification of death still requires commitment. In its conclusion, the text emphasizes the need to broaden discussions and strategies to address issues related to human finitude, considering that new conceptual re-significations always emerge with the progress of science.

Keywords: Bioethical themes. Death. Thanatology. Right to die. Euthanasia.

Resumo

***Vade mecum* sobre o morrer e a morte**

Considerando o impacto da morte em múltiplos aspectos da coletividade humana, este artigo reflete sobre como diferentes culturas, em épocas distintas, relacionaram-se com esse tema, buscando interpretar os vários significados associados à finitude. Para tanto, o estudo parte de uma revisão bibliográfica de abordagem qualitativa. Constata-se que as civilizações que se sucederam ao longo dos séculos têm em comum uma série de barreiras para compreender e aceitar a morte. E, a despeito de novos paradigmas socioculturais, da liberdade de expressão e de toda a evolução tecnológica que caracterizam a sociedade contemporânea, a desmistificação da morte ainda requer empenho. Em sua conclusão, o texto enfatiza a necessidade de ampliar discussões e estratégias para enfrentar as questões relacionadas à finitude humana, levando em conta que novas ressignificações conceituais sempre emergem com o progresso da ciência.

Palavras-chave: Temas bioéticos. Morte. Tanatologia. Direito a morrer. Eutanásia.

Resumen

Vademécum acerca de morir y la muerte

Considerando el impacto de la muerte en múltiples aspectos de la colectividad humana, este artículo reflexiona sobre cómo diferentes culturas, en diferentes momentos, se relacionaron con este tema, buscando interpretar los diversos significados asociados a la finitud. Por lo tanto, el estudio parte de una revisión bibliográfica de un enfoque cualitativo. Se constata que las civilizaciones que se han sucedido a lo largo de los siglos tienen en común una serie de barreras para comprender y aceptar la muerte. A pesar de los nuevos paradigmas socioculturales, la libertad de expresión y toda la evolución tecnológica que caracteriza a la sociedad contemporánea, la desmitificación de la muerte aún requiere compromiso. En su conclusión, el texto enfatiza la necesidad de ampliar las discusiones y estrategias para abordar cuestiones relacionadas con la finitud humana, teniendo en cuenta que siempre surgen nuevas resignificaciones conceptuales con el progreso de la ciencia.

Palabras clave: Temas bioéticos. Muerte. Tanatología. Derecho a morir. Eutanasia.

The authors declare no conflict of interest.

Concept of death through the hourglass

Since the dawn of civilization, queries regarding the finitude of life have had an ambiguous influence on the human race. Although death is one of the most significant somatic markers in individuals' existence and surely symbolizes the maximum degree of human vulnerability, multiple taboos, fears, and uncertainties have always permeated such topic, in all cultures that succeeded each other throughout the centuries, including contemporary society.

In ancient Egypt, passing was not considered an ultimate condition or a final rest, but rather the beginning of a new life in a parallel world. According to archeological records dating back at least 4,000 years and known today as the *Book of the Two Ways*[1], Egyptian civilization painted their sarcophagi to instruct the souls of the deceased on their difficult journey to the realm of Osiris, the God of Death. Later, Egyptians started leaving papyri together with the mummies, which were called the *Book of the Dead* (or the *Book of Emerging Forth into the Light*), with spells, prayers, and various recommendations designed to help the dead in their journey to a new existential dimension after life.

In Greek mythology, Hades was the God of the underworld and King of the dead, the most feared and abhorred deity, according to Plato: *The tales told about what is in Hades – that the one who has done unjust deeds here must pay the penalty there – at which he laughed upon then, now make his soul twist and turn because he fears they might be true*[2]. Importantly, ancient Greece occasionally performed infanticide under the guise of eradicating newborn babies with physical defects, and seriously ill elders could also have their deaths anticipated to alleviate suffering.

In the Roman Empire, whose God of death was Pluto, it was also customary for relatives to kill their malformed children, having this right assured by legislation (Law of the Twelve Tables, Table IV). This dubious custom was stigmatized by Judaism and later by Christianity, which gradually changed cultural standards. Dominion over human life became God's exclusive prerogative, and it was not up to humankind to usurp this divine power.

Resignation in the face of illness or fatal misfortune was the usual conduct in the Middle Ages. In their prayers, Western Christians cried out to God not to be victims of sudden deaths, for suffering and pain fulfilled a redemptive role that benefited the spiritual evolution of the dying. Paradoxically, in this period the Catholic Church was responsible for many incongruities practiced under the guise of defending the Christian faith. St. Thomas Aquinas, as quoted by Engelhardt, even stated in his *Summa Theologica* that heretics *deserve not only to be separated from the Church by excommunication, but also to be separated from the world by death*[3]. To this day, historians have been unable to determine the exact number of victims of the Crusades and the Inquisition.

A common practice in the Middle Ages and in the Modern Age, torturing and sentencing individuals accused of transgressing religious or legal norms of the various kingdoms or countries to death was considered the best alternative to repress practices considered dangerous for the regimes' stability. For example, Tiradentes, the Minas Gerais-born insurgent, was condemned by the Portuguese Crown to "*morte natural para sempre*" [natural death forever], which consisted of hanging, dismemberment of the body, loss of all property and suppression of all civil records referring to the convict's previous existence. Besides monarchs and rulers, the only segment of society that benefited from such measures was medicine, as the corpses of the convicted were occasionally ceded for anatomical studies that contributed exceptionally to developing this science.

Contemporary Age, in turn, changed the social concept of death. Suffering and agony were no longer relevant for spiritual salvation in the end of life. People began to die in hospitals, and no longer at home. The era was rife with revolutions and wars that spread hunger, misery, and death at stratospheric levels. Some countries were directly responsible for eliminating their own civilian population for various discriminatory reasons, such as racism and eugenics. Nazi Germany, for example, was responsible for slaughtering thousands of citizens (current estimates calculate between 70,000 and 200,000 victims) in its eugenics program Aktion T4, between 1939 and 1945[4]. The program included children, adults, and older adults with physical disabilities, epilepsy, mental illness, and other "incurable" pathologies.

 http://dx.doi.org/10.1590/1983-80422021294506

With the advance of medical science, a new definition of death diagnosis emerged. This controversial issue would only be cleared up after the first heart transplant in history, performed by surgeon Christiaan Neethling Barnard in December 1967 at Groote Schuur Hospital in South Africa. The imperative need for the donor to be alive (although dying) when his heart was removed was one of the main criticisms by those who disagreed with this new technique. Objections would only soften in August 1968, when an *ad hoc* committee from Harvard Medical School, chaired by Henry Knowles Beecher [5], established the medical criteria for effective characterization of the concepts of "irreversible coma" and "brain death," clinical situations until then poorly defined.

Today, the phenomenon of death remains shrouded in fear and misunderstanding. Some cultural diversities are quite peculiar, such as the "ghost wedding" tradition that takes place in certain cities in rural China. There still persists the ancient belief that single men over the age of 12 who die before marrying will suffer afflictions in the spirit world and bring many misfortunes upon their relatives. To avoid such adversity, their relatives start looking for other peasant families where the death of an unmarried woman has occurred. Upon finding them, the families arrange the marriage of their deceased children, even though they have never met in life. After a financial dowry is paid to the bride's family, the corpses are exhumed and dressed appropriately for a traditional marriage ceremony. The new spouses are then reburied in a joint grave, and everyone rejoices, believing that they have satisfactorily fulfilled their family duties.

Another controversial custom today consists in the martyrdom and terrorist sacrifices of suicide bombers in defense of a supposedly religious or patriotic cause – a practice already recorded in different times, such as in Ancient Rome (sicarios), in the Turkish-Ottoman Empire (suicide warriors or *bashi-bazouk*) and, more recently, in Japan (*kamikazes*).

Not every cultural expression, however, reflect a tragic or mournful perspective. In Mexico, for example, the traditional Day of the Dead celebrates the ceremonial reunion between people and their deceased relatives with festivities, parades, music, and much merriment. The celebration makes up the list of Intangible Cultural Heritage of Humanity by the United Nations Educational, Scientific, and Cultural Organization (UNESCO) since 2003.

Complex debate in contemporary times

The Latin quote *timor mortis conturbat me* ("fear of death disturbs me") exemplifies the contemporary cultural phenomenon of death denial. Despite thanatology and bioethics exhaustively research on the multiple medical, psychological, legal, and social aspects of death, one can identify the core issue behind most of the discussions on this topic: the suffering present at the end of existence or when facing a serious, progressive illness without favorable prognosis. Among the many debates established in society, some even antagonistic, surely the global consensus converges on a commitment to defend human dignity.

As Kovács [6] points out, controversial questions remain without conclusive answers in contemporary society: can we program the time and circumstances of our own death? Should the right of individuals who have consciously chosen to end their lives early be respected? Can friends, family members, and health care professionals mercifully help a person who wishes to anticipate their own death? Can (or should) medical treatments whose purpose is to prolong the life of patients with a fatal prognosis, despite a progressive worsening of their quality of life, be suspended? Who can effectively decide for terminally ill patients who no longer possess the autonomy to express themselves?

Knowledge of the various types of death contributes greatly to the adequate perception of this phenomenon. Despite being used for the first time in 1623 by philosopher Francis Bacon, in his work *Historia vitae et mortis*, as an adequate treatment for incurable diseases, the term "euthanasia" remains indispensable to understand this complex subject. From the Greek *eu* (good) and *thánatos* (death), the word was initially understood as "good death," a death without pain or a serene death, consisting in a practice by which one sought to shorten, without pain or suffering, the life of a patient known to be incurable. Currently, its concept has changed to

mean the conduct of deliberately ending the life of an ill person. According to Lepargneur, as quoted by Pessini and Barchifontaine, in the 20th century, euthanasia *acquired a pejorative connotation and, little by little, to represent a mere euphemism to signify the painless suppression of life voluntarily provoked by those who suffer or might suffer in an unbearable manner* [7].

Nowadays the word "euthanasia" is polysemic, that is, it has many meanings. But the existing consensus states that the practice depends on the voluntary and explicit request of an autonomous individual who wishes to anticipate death, and with no necessary direct link between euthanasia and terminal illness (consequently, patients with degenerative diseases at any stage of evolution are all included). Although countries like Holland and Belgium have already regulated euthanasia, Brazil categorizes it under crime of homicide, which can be aggravated in case of asphyxia (for example, suffocation with a pillow) or use of poison of any kind (Penal Code, article 121, § 2º, III) [8].

Among the various existing classifications (some quite questionable), we can mention "active euthanasia" (also called "positive" or "direct"), which consists in an action that accelerates or causes death; "passive euthanasia" (or "negative"), which basically consists in an omission to anticipate death or to suspend procedures to prolong life; "voluntary euthanasia" (action that causes death at the patient's request); and "involuntary euthanasia" (action that causes death without the patient's explicit consent, which for many is synonymous with homicide).

Suicide (action that individuals commit against themselves to achieve a fatal outcome) are further defined in two other ways: "assisted suicide," which occurs when one commits the act with the help of one or more people; and "passive suicide," which occurs by omitting measures or procedures that could result in death. In Brazilian legislation, to induce, instigate, or aid suicide is also a crime (Penal Code, article 122) [8].

We have both emphatic defenders and stubborn opponents of euthanasia. The Roman Catholic Church, for example, disapproves of the practice, considering it is a violation of God's law, an offense to human dignity, and a crime against life [9]. The World Medical Association (WMA) ruled in 1987 that euthanasia – the act of deliberately ending a patient's life, even at their own request or that of a close family member – is ethically inappropriate [10]. But it made a timely caveat that this guideline does not prevent physicians from respecting the patient's wishes by allowing the natural course of death in the terminal stage of the disease. This opinion was recently reiterated at the 70th AMM General Assembly held in Tbilisi, Georgia.

Other important definition that frequently appear in the current scientific literature is the term "dysthanasia," from the Greek *dys* (defective act) and *thánatos* (death), proposed in 1904 by Georges Morache [11]. It consists in prolonging the life of a person with incurable disease by extraordinary means, even in deplorable conditions for the patient. The practice is also called "obstinacy" or "therapeutic cruelty" (or even "medical futility," a common term in the United States), as it implies maintaining invasive treatments in patients with no chance of recovery. Dysthanasia usually occurs in well-structured hospitals with many technological resources, since this questionable vital maintenance involves high costs. Prominent personalities such as Franco (Spain), Tito (Yugoslavia), Hirohito (Japan) and Tancredo Neves (Brazil), were famous examples of dysthanasia in history.

Another Greek-derived term often used by poor and underdeveloped countries is "mysthanasia" or "social euthanasia" (although many consider the latter inadequate). Mysthanasia results from the lack of adequate care for thousands of people with physical and mental disabilities or other treatable diseases, throughout their lives, and not just in advanced or terminal stages. It notably affects poor people and is a common cause of premature and undue death. In short, it is a miserable death, outside and before its time. Brazilian writer João Cabral de Melo Neto masterfully addresses this topic in his magnum opus *Morte e vida severina* [Death and Life of a Severino].

The term "*kryptonasia*" refers to another phenomenon whose victims are also predominantly poor people, with low education, older adults and patients with chronic or degenerative diseases [6]. It consists in anticipating the death of critically ill patients or those in terminal phase of a disease, by exclusive deliberation of the healthcare team, to free up vacancies for other critical patients with perspective of recovery, who have yet to obtain

a bed in intensive care units or hospital centers. Kryptonasia occurs without a request from patients or their family members to abbreviate life, and is considered homicide under the Brazilian legislation and in other countries.

"Orthothanasia," in turn, is defined by França as the *suspension of drug or artificial means of life of an irreversible coma patient, considered to be "brain-dead" and with severe impairment of the vegetative life coordination and relational life* [12]. The neologism, derived from the Greek *orthós* (straight, right, correct) and *thánatos* (death), is based on the assumption that death is not a disease to be cured, but something inseparable from life.

Unlike with euthanasia, we have practically no restrictions regarding orthothanasia. In an official statement, the Roman Catholic Church considers it *licit in conscience to make the decision to renounce treatments that would only prolong life precariously and painfully, without, however, interrupting the normal care due to patients in similar cases* [9]. In Brazil, the Federal Council of Medicine (CFM) has established that *in the terminal phase of serious and incurable diseases, the physician is allowed to limit or suspend procedures and treatments that prolong the patient's life, ensuring the necessary care to alleviate the symptoms that lead to suffering, from a comprehensive care standpoint, respecting the will of the patient or their legal representative* [13].

Another extraordinary advance of the 20th century was the modern hospice movement, idealized by Dr. Cicely Saunders aiming at the adequate care of patients with advanced and terminal diseases. Developed in England (more precisely at St. Christopher's Hospice) in the 1960's, this initiative is in full expansion in Brazil and encompasses two main goals: palliative care (which revolutionized therapy for terminally ill patients) and hospice care, offered in places idealized to receive patients who will die in a not too distant future.

In the legal area, where dilemmas stemming from rights and duties establish the foundations of social harmony, archaic (pre)concepts have been reformulated at a rapid pace, enabling the introduction of new interventions, such as advance directives of will, or living will (living will and health care proxies in the United States, and *testament de vie* in France). Thanks to these documents, unfeasible until a few decades ago, a lucid person can now specify in advance the care and treatment they wish to receive or to refuse in the event that they are physically or mentally incapacitated and unable to express their will freely and autonomously. Consequently, it is customary to appoint a proxy to make decisions for the patient. In Brazil, however, this remains a little practiced expression of citizenship.

Outlook for the future

In a historical moment designated as the Fourth Industrial Revolution [14], marked by technological advancements and cultural changes, we paradoxically observe that certain conceptions remain rooted in society, despite the need for reformulation. Despite having evolved, in the last decades, in controversial issues regarding the terminality of human life, we still have a long way to go to demystify this complex phenomenon.

Notwithstanding all the scientific evolution and freedom of expression that characterize the present time, the archaic custom of avoiding interventions or debates related to the multiple implications of death in everyday life persists. Hans Jonas asserts that *no matter how many diseases man finds cures for, mortality does not bend to his cunning* [15].

Besides, other unique demands are now considered due to environmental issues. Such is the case, for example, of discussions about the fate of human bodies. According to official data from the Pan American Health Organization and the World Health Organization [16], approximately 56.9 million deaths were recorded in 2016, which corresponds to 1.8 deaths every second. This data demonstrates the need to address the ecological implications of human finitude, such as scarcity of physical space for new burials, groundwater contamination, and high carbon emissions associated with high-energy consumption in cremations.

The imperative to broaden the debates on this controversial topic goes beyond the limits of mourning or autonomy in establishing the desired moment of death. In an article published in Nature, researchers from Yale University surprised the scientific community by describing an experiment in which they were able to attenuate brain cell death, maintain synaptic activity, restore blood

vessels, and partially preserve brain metabolism in pigs that had been decapitated four hours before the procedure [17]. Despite having no immediate clinical implications, the likelihood that these results will result in remarkable advances in medicine and especially in neurology is great. The most remarkable, however, is its enormous potential to change not only current knowledge, but society as a whole. Long-established and hitherto unquestionable concepts, such as the current diagnosis of brain death and several other medical, legal, political, and social paradigms, may be radically reformulated in an as yet undefined timeframe. New times, new challenges.

Final considerations

A society that is able to interpret death is structured to face the various dilemmas of life. But exorcising anachronistic, prejudiced, and frightening aspects of this phenomenon is not simple. Deconstructing centuries-old archetypes requires motivation, persistence, respect for divergent ideologies, and, above all, unrestricted dialogue based on scientific arguments. Relevant questions remain without definitive answers, such as the right to death and the disrespect for the autonomy of people with incurable diseases. Postponing the inevitable is certainly not the best alternative to face these intricate dilemmas.

Debates on controversies related to death need to be broadened to include all segments of the population, without exclusion by age, ethnicity, gender, social class or level of education. If, on the one hand, one can consider as indispensable the role of bioethicists in driving this process; on the other, one should emphasize the need to expand the discussion beyond the walls of universities and research institutions, bringing it closer to people's everyday life. This strategy can contribute to effectively build a new reality that is congruent with the future we aspire to for our civilization.

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Received: 3.15.2020
Revised: 9.28.2021
Approved: 10.4.2021