The right to health

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BETWEEN LIFE AND DEATH

The right to life is a fundamental human right from which all other human rights derive, especially the right to health, as a crucial part. This right is defined in the Universal Declaration of Human Rights, adopted by the General Assembly of the United Nations in 1948, as well as in the European Convention on Human Rights and Fundamental Freedoms, adopted by the Council of Europe in 1950. It implies that the right to life is protected by law and that no one may be intentionally deprived of it, not even those suffering from incurable illnesses enduring severe pain when death is inevitable, especially if they no longer wish or are unable to bear their suffering.

The question arises, how to treat such patients, those at the very end of life, experiencing intense pain and suffering.

The development of palliative care and sedation, whose primary goal is to ease the suffering and pain of the patient, in the last weeks and days of his life, without the intention of affecting the end of life and increasing accessibility to an ever-widening circle of patients, significantly enhances the quality of life for those who are seriously ill, as well as for their families.

There are numerous ethical dilemmas and legal questions faced daily by medical professionals in this highly delicate area of life and death – an area almost always surrounded by controversy, fear, and the potential for abuse.

***Keywords**: palliative care, terminal sedation, medical ethics, ethical dilemmas, ethical controversies, euthanasia.*

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1. Introduction

The primary goal of medicine is to preserve life. The fight to preserve life makes sense as long as the incurable disease has not reached its terminal stage – after which the focus shifts to alleviating suffering. In everyday clinical practice, ethical dilemmas and legal issues are persistent during the terminal phase of an incurable illness.

The question arises whether a doctor must preserve life "at all costs." In cases of incurable diseases, a doctor does not have a moral or legal obligation to extend life if doing so would result in suffering, pain, and humiliation for the patient. However, we are once again faced with a moral as well as a legal problem: who is the one who determines when the end is and whether it makes sense to prescribe a "slow death" to the dying patient?

Each society has its ethical norms shaped by family, education, tradition, and religion *(Kellehear A., 2000; Kemp C., 2002).* For a physician to make appropriate decisions in these very delicate situations, besides substantial theoretical and clinical knowledge and experience, it is essential to understand the principles of medical ethics. *(Randal F, Downie RS,1996)*

The Hippocratic Oath emphasizes humanity as a core moral tenet, and a key aspect of society is the physician's obligation to assist anyone in need. Even Hippocrates opposed the deprivation of life, even in patients who endure unbearable pain and suffering *(Harris NM, 2001).* However, a physician bears not only moral but also legal, professional, criminal, material, and financial responsibility for actions or inactions that result in significant harm to those who need help *(Vodinelić, 1995).*

2. Medical Ethics

The key principles *(prima facie*) of medical ethics are patient autonomy, patient well-being, the principles of "first, do not harm" *(primum non nocere),* and justice. The ethical principles found in the Hippocratic Oath serve as essential guides for everyday clinical ethical dilemmas *(Harris NM, 2001).* Ethics is defined as the framework for understanding moral life or applying ethical reasoning to medical decision-making *(Bossaert L.L. et al., 2015; ACEP Board of Directors, 2017).*

The autonomy of patients (*yoluntas aegroti suprerna lex*) requires physicians to make decisions that align with the patients' values and beliefs. Patients have the right to choose whether and how they want to be treated. In modern healthcare, particularly in developed countries, patients are at the center of the decision-making process. Autonomy is implemented through free and informed consent, and patients have the right to revoke

consent at any time. However, this raises important questions when it comes to incapacitated patients. If a patient's wishes have been documented previously, these documents are often inaccessible during critical moments, leading to additional ethical dilemmas. In developed Western countries, the standard solution is the use of advance directives – written instructions that outline therapeutic decisions a patient wishes to make in advance, in case they later become incapable of making decisions for themselves. These decisions may include:

1. Decisions made by the patient during life (testament).
2. Decisions made by the authorized representative, the person/s who will make decisions related to the patient's health, if and when he loses the power of judgment.

Patients' decisions must be permanent, valid, and enforceable. According to the Convention on Human Rights and Biomedicine, as of 2010, Article 9 refers to the previously expressed wishes of the patient, which must be taken into account when making decisions.

Our law allows for the appointment of a person to make decisions on behalf of the patient, but it does not define who that person can be or in exactly what situations they are obliged to make decisions. Decisions made in advance – refer to instructions made in advance, of free will, related to treatment, care, and resuscitation, in a situation of incurable disease, when the patient is incompetent to make decisions. Instructions must be written or given verbally to the family or members of the palliative care team and must be documented in the medical history. Significantly, the instructions can be withdrawn at any time if the patient is aware, communicative, and competent to make decisions (*Paris JJ, McCormick RA1981*). With these instructions, the patient can refuse treatment but not care, food, drink, and control symptoms. Also, the patient cannot decide on euthanasia.

The principle of well-being states (*solus aegroti suprema lex*) that any proposed intervention or medication must benefit the patient more than it harms them. This is why evidence-based clinical guidelines are being increasingly adopted, with greater involvement from patients themselves.

The principle of equity (*Justitia*) asserts that health resources should be distributed in a way that ensures everyone has the right to receive the current standard of care, regardless of their social status. Since resources are generally limited, it is recommended that they be allocated to those patients who are most likely to benefit from them.

The principle of "not harm," also known as *"primum non nocere" i*s rooted in the Hippocratic oath. This principle emphasizes the importance of not initiating treatments that could cause more harm than good. Research on ethical principles in Europe

indicates that we rank last, having implemented only one out of the 41 ethical principles examined *(Mentzelopoulos S.D. et al., 2016).*

In the modern healthcare system, where the patient is at the center of interest, the relationship between the patient and the doctor is crucial. Effective communication and a strong doctor-patient relationship are essential, particularly when caring for patients whose lives are nearing their end *(Lanken P. et al., 2008; M.Lukić-Šarkanović 2024)* Empathy represents the ability to understand the patient's feelings, situation, and wishes, but also to show and express understanding *(Gremigni P., Casu G., Sommaruga M., 2016)* Empathy is a desirable trait in healthcare workers, as those with higher levels of empathy are thought to utilize the information obtained from patients more effectively, thereby helping to alleviate their suffering *(Vachon D., Lynam D., 2015; Kiersma M.E. et al., 2013; Costello J., 2006).*

3. Palliative Care

The goal of palliative care is to alleviate suffering and pain, preserve dignity, and achieve the best possible quality of life for the patient and their family, given the circumstances. It affirms life but also accepts death as an inevitability, neither rushing nor postponing it. This understanding and acceptance of death is a key aspect of palliative care, which also focuses on relieving pain and other unwanted symptoms, and integrating the psychological, social, and spiritual aspects of caring for a seriously ill patient *(Miličević N., Kovčin V., Babić M., 2001)*

The patient suffers not only pain and other physical symptoms, but also psychological (fear of death and the unknown), social (feeling of abandonment and loneliness), and spiritual pressure (feeling of meaninglessness, hopelessness, despair). Cicely Saunders called all of this "total" pain and directed the care of patients in the last months or weeks of life towards this. *(Jurišić A., 2001)*. In this way, ethical norms, individual autonomy, harmlessness, and charity are respected, which is based on the patient's right to decide on his treatment. In medicine, the main goal is to cure the patient, and death is considered a failure. In palliative care, the goal is to relieve pain and suffering, and death, which happens spontaneously, is regarded as a success *(Brkljač M., 2008).*

Despite the resolution of many issues, ethical dilemmas and controversies related to end-of-life decisions remain prevalent today. The most common of these are:

3.1. Whether and how to inform the patient about their condition and prognosis

To respect the principle of autonomy, patients must receive accurate and complete information about their illness and its prognosis, enabling them to make informed decisions about their treatment. Patients have the right to refuse this information or to request that it be shared with a family member or close friend instead. The traditions and religions of certain nations continue to have a significant influence on this decision. In many Western countries, including those in Western Europe and the USA, the obligation for the patient to be informed about their illness is regulated by law as mandatory. Conversely, in some less developed countries, this remains an ethical dilemma, and patients are often not informed about their illnesses, despite many of these countries having laws that require such disclosure.

3.2. Futility of treatment

In palliative care, every decision made by healthcare professionals must be based on the fundamental ethical principles in medicine. Before undertaking any treatment, intervention, or medication, it must be ensured that the decision is in the patient's best interest and that the principles of fairness and "first not harm" are respected. Making this decision is very complex, and it is necessary to consider each specific case individually, as well as which of the fundamental ethical principles is crucial in a given situation. You should always consider the opinion of the doctor, the patient's opinion, and the patient's family, and only then make a decision *(Moratti S. 2009)*

3.3. The Principle of Double Effect

Considering that these are patients with an advanced, incurable disease, there is a risk that specific interventions or medications may ultimately lead to death. This situation raises important ethical questions about whether to pursue treatments that could relieve suffering, even if there is a potential for a fatal outcome. Should we prioritize alleviating symptoms at the risk of hastening death, or should we allow the patient to endure suffering? This dilemma is a fundamental ethical question (Amy T.,Andrew D.,(2025).

3.4. Nutritional support and rehydration

A frequent dilemma of the patient's family as well as individual healthcare workers is whether patients with an advanced incurable disease, in the terminal phase, need nutritional support, given that most are cachectic and have a poor appetite or a complete loss of appetite. The cause of physical weakness and decay is the malignant disease

itself, but also numerous metabolic and immunological disorders. No evidence suggests that forced feeding affects survival or improves quality of life, but it can only prolong the patient's dying and suffering phase. The situation is similar to fluid intake. In the terminal phase, patients typically do not experience thirst. They can often complain about dry mouth, but the cause, apart from dehydration, is frequently attributed to the use of oxygen, various medications, oral fungal infections, and other factors. If the patient has an open intravenous line, it is recommended to administer 500-1000 mL of 0.9% saline solution in slow drips.

3.5. Cardiopulmonary Resuscitation (CPR)

Resuscitation is a medical procedure that can restart the heart and potentially save a life. However, more commonly, it may prolong an incurable illness, thus extending the suffering of both the patient and their family. CPR is considered ineffective when the likelihood of achieving a good quality of life after the procedure is minimal. One key factor that makes treatment ineffective is the absence of a medical indication for its use. It is important to note that the decision not to initiate resuscitation does not require consent from the patient or their family members, who often have unrealistic expectations regarding its potential success and benefits.

4. End-of-Life Care

When a person reaches the final stage of life, deciding not to continue medical interventions that will no longer bring benefit is never easy. It requires careful thought, compassion, and honesty. In these moments, the most crucial step is to listen to the patient and to their family as well. Their wishes should always be respected and balanced with the guidance of the palliative care team. The actual goals of care in the last hours of life are simple yet profound: to provide peace, dignity, and support on every level – physical, emotional, and spiritual. Symptoms can be relieved so that the person's final moments are spent in comfort. Small things often mean the most: keeping the patient clean, caring for their mouth, and making sure they rest in a comfortable position. Families are invited to participate in whatever way they feel comfortable. Some may want to stay close, others may not have the strength to watch their loved one fade. Both are natural, and both should be respected. What will remain in their memory forever are those last days and hours.

Recognizing when death is near is not always straightforward. Signs may include extreme weakness, prolonged periods of sleep, staying in bed all the time, confusion or drifting into a semi-conscious state, little or no interest in food or water, and difficulty swallowing (*Murray, S., Kendall, M., Boyd, K., & Sheikh, A., 2005*). In the final 48 hours,

families may observe symptoms such as noisy breathing, restlessness, pain, nausea, vomiting, or shortness of breath.

Because of weakness, many patients are unable to clear secretions in their throat, leading to what is sometimes called a 'death rattle.' Though harmless to the patient, it can be distressing for family members. Medications, repositioning, and gentle suction can help.

- Terminal Delirium or Agitation can occur when the mind is no longer clear. If reversible causes have been ruled out and restlessness is severe, sedation may be considered to allow the patient to find calm.
- Breathlessness (Dyspnea) is often one of the most challenging symptoms – not only physically but also emotionally (*Corner et al. 1997*). The goal of care is not just to alleviate the sensation, but also to ease the fear that accompanies it. Gentle words, empathy, relaxation, or even quiet meditation can help. In more difficult cases, morphine can be safely used to bring comfort, with careful attention to dosage. The fear of side effects should never prevent relief from suffering.
- Nausea and Vomiting: In the final hours, nausea can be alleviated with anti-nausea medications, typically administered as suppositories.
- Pain is one of the greatest fears at the end of life. In fact, fear of pain often outweighs fear of death itself. With the proper medications – opioids and, if needed, other supportive drugs for nerve pain – suffering can be controlled. Since swallowing may be difficult, medicines are often administered rectally or subcutaneously, which is a gentle and effective method.

5. Palliative (Terminal) Sedation

As a patient's condition deteriorates and death approaches, the intensity of physical, emotional, social, and spiritual symptoms often increases, significantly affecting both the patient's quality of life and that of their family (*Claessens et al., 2007*). To relieve these symptoms and maintain a degree of functioning, various medications are used – primarily sedatives, hypnotics, and analgesics (most commonly opioids). This practice is referred to as palliative sedation (also known as terminal sedation).

Palliative sedation is based on several criteria:

1. The patient suffers from an advanced, incurable disease.
2. The disease is expected to progress naturally to death within a few days.
3. Sedation itself is not the direct cause of death.
4. It does not alter the dying process, meaning it neither hastens nor delays death.

5. It is performed at the request of a seriously ill patient in the terminal phase of the disease (*Muller Buch, Andres, Jehser, 2003*).

This practice represents one of the most controversial bioethical issues in palliative care. Euthanasia advocates often refer to it as "indirect euthanasia," yet it is essential to distinguish between the two clearly. Euthanasia involves the deliberate termination of life through active medical intervention. In contrast, palliative sedation aims to relieve unbearable suffering and control symptoms without intending to end life. The intention behind each practice is the crucial difference, both ethically and legally (*Cohen et al., 2005*).

Palliative sedation is regarded as a "therapy of last resort," ethically justified by the principle of double effect. Its primary goal is not to shorten life but to alleviate suffering in patients whose symptoms cannot be controlled by any other means. For this reason, it must be clearly separated from euthanasia and assisted suicide. This raises several important questions, the most common being: who makes the decision? If the patient is capable of decision-making, their autonomy must be respected. If not, the family may be involved, which can be a heavy moral burden. Another dilemma is whether it is ethically and legally acceptable for the medical team to make such a decision independently.

Patients in palliative care units require close monitoring by a specially trained team. Properly conducted terminal sedation does not shorten life; its sole purpose is to relieve suffering. In making decisions, the team evaluates the clinical situation, potential risks, expected benefits, and the patient's physical, functional, and psychosocial needs. The decision-making process typically involves several meetings between the multidisciplinary team and the patient's family to reach a shared agreement. Ultimately, decisions are made in accordance with the patient's wishes (if competent), medical indications, the current clinical condition, and fundamental ethical principles.

The Ethical Working Group of the European Association for Palliative Care, a strong advocate of palliative care, supports the use of palliative sedation to address the concept of "total pain." At the same time, the group firmly rejects euthanasia as the sole solution to suffering.

6. Euthanasia and Brain Death

Euthanasia, derived from the Greek words "eu" (good) and "thanatos" (death), refers to the intentional act of hastening death in order to relieve a patient's suffering. It is often described as a "good death," "pleasant death," "merciful death," "dignified death," or "assisted dying." In its most common sense, the term refers to active euthanasia, which may be either direct – when a physician administers a lethal dose of medication

– or indirect, when a physician prescribes the medication but the patient administers it themselves. Alongside active euthanasia, there is also passive euthanasia, which may likewise be direct – through the withdrawal of ongoing life-sustaining treatment – or indirect, when life-saving measures are not initiated in the first place (*Wreen, 1988; Lukić-Šarkanović, 2021*).

When an individual makes a conscious and voluntary request to end their life to escape further suffering, this is known as voluntary euthanasia. Conversely, involuntary euthanasia refers to circumstances in which the patient cannot make such a decision, such as in cases of coma or severe mental or physical impairment (*La Follette, 2002*).

Numerous studies – both from neighboring countries and more developed nations – demonstrate that attitudes toward euthanasia are influenced by gender, previous experiences, and the religious beliefs of patients and their families. An extensive study including 33 European countries found statistically significant differences in acceptance based on socio-demographic factors: men and individuals with higher education levels were more supportive. In contrast, acceptance declined with stronger religious conviction (Cohen et al., 2006). Other research has confirmed that religiosity is one of the strongest predictors of opposition to euthanasia (*Boyd & Chung, 2012; College of Physicians and Surgeons of British Columbia, 2016; Danyliv & O'Neill, 2015*). In line with this, the world's significant religions remain firmly opposed to any form of euthanasia, consistently rejecting actions intended to hasten death (Jerotić, 2008).

The discussion of euthanasia is inseparably linked to the medical and legal concept of death. Death is understood most precisely as brain death, which may involve the irreversible cessation of all brain activity, including the brainstem, or the complete failure of higher cortical functions. Importantly, isolated neocortical death – representing only the loss of consciousness while brainstem activity persists – does not, in itself, signify the death of the individual (Jukić et al., 2013).

According to widely accepted medical definitions, brain death is established when there is irreversible cessation of both brain and brainstem function, often accompanied by irreversible loss of circulatory and respiratory activity. The essential clinical findings include deep coma, absence of all brainstem reflexes, and apnea (Guidelines JAMA, 1981). Common causes include severe head trauma, hypertensive intracerebral or subarachnoid hemorrhage, hypoxic-ischemic brain injury, and fulminant liver failure (Goila & Pawar, 2009). Because certain conditions may mimic brain death, it is essential to exclude them before making the diagnosis. Mimics include profound hypothermia, intoxication with barbiturates or other CNS depressants, Guillain-Barré syndrome, locked-in syndrome (where patients are fully conscious but unable to move or communicate), and

akinetic mutism (severe apathy with preserved awareness but very slow voluntary movements, confirmed by EEG) (Gelb & Robertson, 1990).

The loss of brain function also produces systemic physiological instability, manifesting as loss of vasomotor control, respiratory failure, arrhythmias, impaired thermoregulation leading to hypothermia, diabetes insipidus, and hypothyroidism. Modern intensive care measures and advanced mechanical ventilators, however, can maintain vital functions even after complete and irreversible brain failure (Goila & Pawar, 2009).

Diagnosis of brain death is therefore based on a structured clinical examination, which must confirm deep coma with no response to external or internal stimuli, mid-dilated or semi-dilated non-reactive pupils, absent oculocephalic and vestibular reflexes, and absence of corneal and tracheal reflexes. In addition, the atropine test and apnea test are applied, supplemented by confirmatory investigations such as EEG, brainstem auditory evoked potentials (BAEP), and somatosensory evoked potentials (SSEP) (Morgan, Soriano & Sloan, 2013). Cerebral blood flow studies – including angiography, transcranial Doppler, MRI/MRA, CT angiography, or radionuclide perfusion scintigraphy – are also used when necessary (Wijdicks, 2011). By law and clinical guidelines, brain death must be confirmed by a medical commission, typically composed of an anesthesiologist-intensivist and a neurologist or neurosurgeon.

The concept of brain death was first introduced in 1959, laying the foundation for modern transplantation medicine (Mollaret & Goulon, 1959). Accurate and timely diagnosis of brain death, together with the precise documentation of findings and the exclusion of reversible conditions, ensures the ethical use of organs from brain-dead donors, supports the progress of transplant medicine, and protects physicians from criminal liability (Truong & Miller, 2008).

7. Conclusion

A logical and ethical dilemma emerges regarding the existence of a boundary and whether any boundary can be crossed when it comes to making decisions about life and death. Additionally, who holds the authority to determine the fate of another person's life?

How to act in the phase "between life and death", when the patient's suffering is enormous, and death is inevitable. In addition to physical, he is also faced with numerous spiritual and social problems. Deciding whether to end life or to allow the patient to spend their final days and hours without suffering or pain, while maintaining dignity through modern medications.

Palliative sedation, with all its drawbacks, is the ideal solution in countries and cultures similar to ours. It affirms life but also accepts death, does not accelerate or delay it, relieves pain and other unwanted symptoms, and integrates psychological, social, and spiritual aspects of caring for a seriously ill patient.

The Ethical Working Group of the European Association for Palliative Care supports the use of palliative sedation as part of managing "total pain." However, it does not endorse euthanasia as the sole solution to end-of-life issues.

Healthcare workers should understand and apply ethical principles in all aspects of their work, especially before they get involved in the decision-making process related to the end of a patient's life.

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