

Some Ethical Concerns About End of Life: A Paradigm Shift From Ars Moriendi to Medicalized Death

Yaşam Sonuna Dair Bazı Etik Kaygılar: Ars Moriendi'den Tıbbileştirilmiş Ölüme Bir Paradigma Değişimi

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Abstract

Medicine has several goals, including preventing and curing diseases, relieving pain and suffering, and promoting and maintaining the mental and physical health of the person from birth to death. Thanks to medical and technological developments in the last century, medicine has started to provide the opportunity to live longer. However, whether a longer life leads to a better life is debatable. Before these developments, death was regarded as a natural and inevitable end and mostly handled with religious approaches, such as *Ars moriendi*. However, these medical and technological advances have caused a misleading perception that medicine has the power to achieve every desired outcome. Under the influence and pressure of this misleading situation, people began to demand aggressive treatments, like resuscitation, mechanical ventilation, artificial nutrition and hydration, and chemotherapy. Of course, these medical interventions can be lifesaving for some patients. However, in the case of incurable conditions, such as metastatic cancers, Alzheimer's disease, or advanced organ failure, aggressive treatment methods often fail to produce promising results; on the contrary, they place a variety of burdens on patients, families, and society, as significantly reducing patients' quality of life, causing unrealistic hopes, and exhausting limited health resources. In this context, the article aims to briefly examine the change in people's perception of death and the dying process and to evaluate its de facto and ethical impacts. This study shows that medical and technological breakthroughs have significantly changed people's comprehension, acceptance, and perception of death, which made death no longer a natural end, but a medical failure. In other words, a medical interventions-based death, called medicalized death, has replaced a religion-based death. As a result of this change, the social, spiritual, and emotional aspects of death and the dying process are ignored for the sake of excessive and ineffective medical interventions. This situation brings about a critical shift in where, how, and when to die, and produces various ethical problems regarding the principles of respect for autonomy, non-maleficence, and justice. The present article demonstrates that most people want to die at home and spend their last days with their families. However, due to medical interventions, many die in healthcare facilities while on medical treatments and machines. In this context, this study recommends home-based palliative care services encompassing social, emotional, and spiritual support instead of aggressive medical interventions at end-of-life. Home-based palliative care will enable individuals to spend the last days of their lives at home with their loved ones, receive emotional and spiritual support, and prevent themselves, their families, and society from unnecessary and futile medical expenses. In conclusion, in light of the principles of respect for autonomy, non-maleficence, and justice, in end-of-life issues, medicine should focus on improving patients' quality of life, providing patients with social, emotional, and spiritual support, and ensuring that patients have the opportunity to spend their last days of life with their family members, which can most suitably be achieved through home-based palliative care.

Keywords: *Ars Moriendi*, Medicalized Death, End of Life, Ethical Challenges, Palliative care.

Özet

Tıbbın, hastalıkları önlemek ve iyileştirmek, ağrı ve ıstırapı dindirmek ve erken ölümleri engellemek dâhil olmak üzere, doğumdan ölüme kadar kişinin ruh ve beden sağlığını geliştirmek ve sürdürmek şeklinde çeşitli amaçları bulunmaktadır. Son yüzyıldaki, tıbbi ve teknolojik gelişmeler sayesinde, tıp, daha uzun yaşama imkânı sağlamaya başlamıştır. Ancak, daha uzun yaşamın, daha iyi bir yaşam sağlayıp sağlamadığı konusu tartışmalıdır. Bahsi geçen gelişmelerden önce, ölüm, doğal ve kaçınılmaz bir son olarak kabul edilmekteydi ve çoğunlukla *Ars moriendi* gibi dini yaklaşımlarla ele alınmaktaydı. Fakat, söz konusu tıbbi ve teknolojik gelişmeler, tıbbın, her istenilen sonucu elde etme gücü varmış gibi yanıltıcı bir algıya yol açmıştır. Bu yanıltıcı durumun etkisi ve baskısı altında, insanlar, resüsitasyon, mekanik ventilasyon, yapay beslenme ve hidrasyon ve kemoterapi gibi agresif tedaviler talep etme yoluna gitmeye başladılar. Elbette bu tıbbi müdahaleler, bazı hastalar için hayat kurtarıcı nitelikte olabilmektedir. Ancak, metastatik kanserler, Alzheimer hastalığı veya ilerlemiş organ yetmezlikleri gibi tedavi imkânı olmayan hastalıklar durumunda, agresif tedavi yöntemleri çoğunlukla umut verici sonuçlar üretmemektedir; tersine, bunlar, hastalara, ailelere ve topluma, hastaların yaşam kalitesini önemli ölçüde düşürmek, gerçek dışı umutlara neden olmak ve sınırlı sağlık kaynaklarını tüketmek şeklindeki yükler getirmektedir. Bu bağlamda, makale, insanların ölüm ve ölüm süreci algısındaki değişimi kısaca incelemeyi ve bunun fiili ve etik etkilerini değerlendirmeyi amaçlamaktadır. Bu çalışma, tıbbi ve teknolojik alanlardaki ilerlemelerin, insanların ölümü anlama, kabul etme ve algılama biçimlerinde önemli değişikliklere yol açtığını ve bu değişikliklerin etkisiyle, ölümün artık doğal bir son değil, tıbbi bir başarısızlık olarak görülmeye başladığını göstermektedir. Başka bir ifadeyle, tıbbileştirilmiş ölüm olarak adlandırılan, tıbbi müdahalelere dayalı bir ölüm anlayışı, din temelli bir ölüm anlayışının yerini almıştır. Bu değişimin bir sonucu olarak, ölüm ve ölüm sürecinin sosyal, manevi ve duygusal yönleri, aşırı ve sonuç doğurmayan tıbbi müdahaleler uğruna göz ardı edilmektedir. Bu durum, nerede, nasıl ve ne zaman ölüneceği konularında ciddi bir değişim meydana getirmekte ve özerkliğe saygı gösterme, zarar vermeme ve adalet ilkeleri temelinde çeşitli etik sorunlar üretmektedir. Mevcut makale, insanların çoğunluğunun evde ölmek ve hayatlarının son günlerini aile üyeleriyle birlikte geçirmek istediğini göstermektedir. Ancak agresif tıbbi müdahaleler nedeniyle, bu insanların birçoğu sağlık kuruluşlarında, tıbbi müdahalelere ve cihazlara bağlı biçimde ölmektedirler. Bu çerçevede, söz konusu bu çalışma, hayatın son döneminde, agresif tıbbi tedaviler yerine, sosyal, duygusal ve manevi desteği de kapsayan evde palyatif bakım hizmetlerini önermektedir. Evde palyatif bakım hizmetleri, bireylere, ömürlerinin son günlerini kendi evlerinde sevdikleriyle birlikte geçirmelerine, duygusal ve dinsel destek almalarına ve kendilerini, ailelerini ve toplumu gereksiz ve faydasız tıbbi masraflardan kurtarma imkânı sağlayacaktır. Sonuç olarak, yaşamın sonuna dair konularda, özerkliğe saygı, zarar vermeme ve adalet ilkeleri ışığında tıp, hastaların yaşam kalitesini iyileştirmeye, hastalara sosyal, duygusal ve manevi destek sağlamaya, hastaların hayatlarının son günlerini aile bireyleriyle birlikte geçirmelerine olanak sağlamalıdır, ki bahse konu bu amaçları sağlamanın en uygun yolu evde palyatif bakım hizmetleridir.

Anahtar Kelimeler: *Ars Moriendi*, Tıbbileştirilmiş Ölüm, Yaşamın Sonu, Etik Sorunlar, Palyatif bakım.

Introduction

Public health improvements, medical advances, and technological developments have increased average life expectancy worldwide. According to the U.S. National Institute on Aging and the World Health Organization, the percentage of people aged 65 or older, which was 8% in 2010, will be 16% of the world population in 2050, and the aging population will increase by 250% in developing countries and 71% in developed countries between 2010 and 2050.¹ Additionally, the number and percentage of deaths resulting from chronic diseases, including cancer, dementia, cardiovascular diseases, and diabetes, have been growing, which means that many deaths have been occurring through a predictable period.² These changes in the aging population and the pattern of dying indicate administrative, financial, and ethical challenges.

Preventing premature death and ensuring a peaceful death is a fundamental goal of medicine.³ Even though referring to a subjective matter, the concept of premature death is generally understood based on available medical opportunities and the possibility of restoring and maintaining certain human functions in light of social and cultural comprehension.⁴ However, contemporary medical ethics considers the person the major – or the only – agent who can decide on what premature death is. As Jonsen et al. emphasize, the principle of respect for persons or respect for autonomy requires “acknowledging the moral right of every individual with decision-making capacity to choose and follow his or her own plan of life and actions.”⁵ In this view, an individual with the decision-making capacity has the right to make all end-of-life decisions about her/his life. This right, which originates from the right to self-rule or self-governance, also allows the person to interpret the meaning of her/his quality of life.⁶ Medical conditions or state of illness should not deprive the

¹ U.S. National Institute on Aging National Institutes of Health and World Health Organization, *Global Health and Aging* (National Institute on Aging National Institutes of Health and World Health Organization, Publication no. 11-7737, 2011), 2-6.

² World Health Organization, “The Top 10 Causes of Death” (Accessed 5 January 2023).

³ The Hastings Center Report, “The Goals of Medicine: Setting New Priorities”, *The Hastings Center Report* 26/6 (1996), 13-14.

⁴ The Hastings Center Report, “The Goals of Medicine: Setting New Priorities”, 13.

⁵ Albert R. Jonsen et al., *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (New York: McGraw Hill Education, 2015), 49.

⁶ Tom L. Beauchamp - James F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, 2013), 101.

patient/person of enjoying the right to self-governance, the insight into her/his quality of life, and decisions about medical interventions.⁷ However, in the event of a lack of decision-making capacity, surrogates become decision-makers with the risk of making decisions inconsistent with patients' preferences, wishes, and values.⁸

The *Ars moriendi*, also known as the art of dying, is a concept going back to the Bubonic Plague (Black Death) outbreak that killed millions of people in Europe.⁹ According to James M. Murphy and John Silke, the *Ars moriendi* consists of "two texts written in Latin around the 15th century that offered advice on how to die well according to the Christian ideals of the time."¹⁰ As Carlo Leget underscores, in the Roman Catholic tradition, the *Ars moriendi* "has been a guide to a good death for many generations" by accepting and describing death through a religious perspective.¹¹ The *Ars moriendi* does not only refer to the death of the elderly but death at any age.¹² Therefore, regardless of the time and form of death, the *Ars moriendi* points out the absolute power of God on life, death, and after death and suggests having faith in His control and decision.

However, especially in parallel with medical and technological advances, the impact of the religion-based standpoint on the death and dying process has weakened. Antibiotics, artificial nutrition and hydration, mechanical ventilation, resuscitation, chemotherapy, etc., have allowed medicine to play a significant role in sustaining life. Even though these medical tools and opportunities have lifesaving functions, excessive utilization of them at the end of life, which is called medicalized death, causes patients to stay on medical devices and interventions until death.¹³ For this reason, it is also possible to deem medicalized death as the opposite side of palliative care.¹⁴ Medicalized death represents life-sustaining interventions until death, whereas palliative care intends to improve and maintain the patient's quality of life by providing pain management and social, emotional, and spiritual

⁷ ML Slevin et al., "Who Should Measure Quality of Life, the Doctor or the Patient?", *British Journal of Cancer* 57 (1988), 109–112.

⁸ Bernard Lo, *Resolving Ethical Dilemmas: A Guide for Clinicians* (Philadelphia: Wolters Kluwer, 2020), 83.

⁹ Dugdale, "Dying, a Lost Art", *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 3-7.

¹⁰ James M. Murphy - John Silke, "Ars Moriendi; The Art of Dying well – New Insights into the Molecular Pathways of Necroptotic Cell Death", *EMBO Reports* 15 (2014), 155.

¹¹ Carlo Leget, "Retrieving the Ars Moriendi Tradition", *Medicine, Health Care and Philosophy* 10 (2007), 313.

¹² Arthur E. Imhof, "Ars Moriendi: How to Live and How to Die", *Historical Social Research* 22/1 (1997), 195.

¹³ Benyamin Schwarz - Benson Jacquelyn, "The "medicalized death": Dying in the Hospital", *Journal of Housing for the Elderly* 32/3-4 (2018), 379-430.

¹⁴ David Field, "Palliative Medicine and the Medicalization of death", *European Journal of Cancer Care* 3/2 (1994), 58-62.

support according to the patient and her/his family's preferences.¹⁵ In other words, medicalized death only focuses on prolonging life through medical interventions, while palliative care concentrates on quality life through medical, social, emotional, and spiritual support.

In this context, the present paper aims to briefly expound on the paradigm shift from the Ars moriendi to medicalized death and assess the pertinent ethical concerns in light of the issues of where, how, and when to die and in accordance with social responsibility, respect for autonomy, beneficence, non-maleficence, and justice. This article not only appraises medicalized death from a critical stance but also points out the relevant ethical problems and proposes home-based palliative care to promote patients' quality of life in their last days and alleviate the connected ethical concerns.

1. Primary Challenges

Death is a natural and inevitable phenomenon. The Quran's verse "every soul will taste death" is a religious expression of that natural reality.¹⁶ However, increasing medical interventions have remarkably changed the perception of the death and dying process. Lydia S. Dugdale regards the medical engagements in the death and dying process as the deterioration of the Ars moriendi (the art of dying) and the emergence of medicalized death.¹⁷ Janna C. Merrick evaluates the matter of death and dying as the issue of how and where to die.¹⁸ Merrick's approach can be expanded on where, how, and when to die to more comprehensively evaluate how the Ars moriendi has transformed into medicalized death.

1.1. Where to Die

The central issue surrounding death and dying is mainly about how to make a good death possible. The perception of a good death is subjective because some can consider it a painless or sudden death, while others may accept it as death occurring at home.¹⁹

¹⁵ Timothy W. Kirk - Margaret M. Mahon, "National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients", *Journal of Pain and Symptom Management* 39/5 (2010), 914.

¹⁶ *Quran.com* (Accessed 14 January 2023), el-Ankabut 29/57.

¹⁷ Lydia S. Dugdale, "Dying, a Lost Art", *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 3.

¹⁸ Janna C. Merrick, "Death and Dying: The American Experience", *End-of-Life Decision Making: A Cross-National Study*, ed. Robert H. Blank and Janna C. Merrick (Cambridge; London: The MIT Press, 2005), 219.

¹⁹ Stephen R. Latham, "Pluralism and the "Good" Death", *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 33.

Nevertheless, regardless of various perceptions regarding the term good death, the primary medical and ethical goal is to allow each person to fulfill her/his good death. Therefore, the matter of where to die is an essential point in the end-of-life process that generates personal, social, medical, and economic consequences. Studies demonstrate that dying at home is not only most people's wish but also a primary indicator of a good death for most people.²⁰ Nevertheless, the number of deaths at home has remarkably decreased in many countries, including the United States and Europe.²¹ This shift is an ongoing change in Western attitudes toward death and dying parallel medical and technological developments.²²

People's wish regarding where to die composes the personal aspect of the issue. The reasons behind this wish may vary, and granting or ignoring it creates happiness or frustration. Dying at home also indicates and requires a strong social and family commitment. However, changes in social and family bonds and lifestyle as well as difficulties in taking care of patients with severe chronic diseases, such as cancer and Alzheimers, make healthcare institutions inevitable places for most people where to die.²³ Atul Gawande highlights this challenge and states, "[y]our chances of avoiding the nursing home are directly related to the number of children you have, and ... having at least one daughter seems to be crucial to the amount of help you will receive."²⁴ Therefore, dying at home or somewhere else is not only associated with personal wishes but also a social structure.

Medical and financial dimensions are two other important matters of where to die because being at home or in a healthcare facility and the type of facility directly reflect the kind of medical care and the number of costs. Whether utilizing aggressive treatment or palliative care, being in a hospital or a nursing home, or receiving hospice care at home or in a skilled nursing home determines the forms of medical care and their costs. End-of-life care denotes one of the most expensive healthcare services in some countries like the United

²⁰ Joachim Cohen et al., "Which Patients With Cancer Die at Home? A Study of Six European Countries Using Death Certificate Data", *Journal of Clinical Oncology* 28/13 (2010), 2267.

²¹ M. Therese Lysaught, "Ritual and Practice", *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 73.

²² Philippe Aries, *Western Attitudes Toward Death from the Middle Ages to the Present*, trans. Patricia M. Ranum (Baltimore: The Johns Hopkins University Press, 1974), 87-88.

²³ Daniel Callahan, "The Elderly and Dementia", *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 149-152.

²⁴ Atul Gawande, *Being Mortal: Medicine and What Matter in the End* (New York: Metropolitan Books, 2014), 79.

States.²⁵ However, as Gawande underlines, it is questionable whether certain forms of end-of-life care, especially aggressive treatments provided in hospitals, which are the most costly services, produce meaningful benefits.²⁶ According to the study by Jennifer S. Temel and her colleagues, receiving early palliative care generates a higher quality of life and a longer life span for patients with metastatic non-small-cell lung cancer instead of aggressive treatment.²⁷ From this perspective, in general, palliative care has a significant function to provide patients with socially, spiritually, and financially better outcomes. However, the content and scope of care and the place where palliative care is received play a prominent role in the potential benefits and costs for patients, their families, and societies.²⁸

1.2. How to Die

The issue of how to die is associated with medical interventions during the process of dying. Lydia S. Dugdale expounds on this matter by addressing the transformation of the Ars moriendi into medicalized death.²⁹ As Dugdale accentuates, the Ars moriendi articulates that “the dying faithful should not fear death, since God is in control of every moment, including death,” and a good death can be achieved “by leading a repentant and righteous life.”³⁰ Even though the Ars moriendi represented a religious approach to explaining how a good death is possible and why death should not be feared, this perspective, which deems death a natural phenomenon, had also influenced secular approaches for many centuries until medical and technological advances gained sufficient ability to impact the time and manner of death.³¹

Pharmaceutical, medical, and technological improvements in the 20th century, including the discovery of penicillin, X-ray technology, and resuscitation and ventilation devices, have produced life-prolonging opportunities and consolidated medical power.³² These changes generated a paradigm shift by transferring the role of religion in the

²⁵ Gawande, *Being Mortal: Medicine and What Matter in the End*, 153.

²⁶ Gawande, *Being Mortal: Medicine and What Matter in the End*, 153, 177-178.

²⁷ Jennifer S. Temel et al., “Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer”, *The New England Journal of Medicine* 363/8 (2010), 733-742.

²⁸ Li Yiting et al., “End-of-Life Care in China: A View from Beijing”, *End-of-Life Decision Making: A Cross-National Study*, ed. Robert H. Blank and Janna C. Merrick (Cambridge; London: The MIT Press, 2005), 35.

²⁹ Dugdale, “Dying, a Lost Art”, 3.

³⁰ Dugdale, “Dying, a Lost Art”, 7.

³¹ Dugdale, “Dying, a Lost Art”, 3.

³² David Cutler - Ellen Meara Cutler, “Changes in the Age Distribution of Mortality over the 20th Century” (Accessed 8 April 2023), 1-4.

perception of death to medicine. Atul Gawande emphasizes this alteration by stating, “scientific advances have turned the process of aging and dying into medical experience, matters to be managed by health care professionals.”³³ Before the mentioned breakthroughs, under of a lack of medical therapies, the *Ars moriendi* referred to the acceptance of death and submission to death-causing factors. However, medical advances have created alternatives and expanded the number of options when encountering a life-threatening disease or incident. As a result of this situation, most of the deaths have recently occurred after long periods of medical interventions.³⁴ In other words, medical improvements have engendered enormous potential for prolonging and shaping the manner of the dying process. For instance, requesting resuscitation or comfort measures only, receiving aggressive treatment or palliative care, or accepting or refusing palliative sedation determines how to die. For this reason, death and dying are no longer merely issues of accepting fate but are also subject to the type and amount of medical treatments and interventions.

1.3. When to Die

Medical and technological advances also notably affect the time of death. Especially the use of antibiotics, resuscitation and ventilation facilities, and artificial nutrition and hydration remarkably influence the timing of death. Providing or withholding/withdrawing life-sustaining support carries a crucial role in when to die. According to Farr A. Curlin, more than two in three Americans die at a healthcare institution, which means that people continue receiving healthcare services until death.³⁵ However, as Curlin underlines, the overuse of healthcare facilities, particularly hospitals, and life-sustaining opportunities is a primary concern due to its ethical, religious, and financial ramifications.³⁶ Philippe Aries describes the excessive use of medicine at the end of life by saying, “[d]eath is a technical phenomenon obtained by a cessation of care, a cessation determined in a more or less

³³ Gawande, *Being Mortal: Medicine and What Matter in the End*, 6.

³⁴ Gawande, *Being Mortal: Medicine and What Matter in the End*, 156-157.

³⁵ Latham, “Pluralism and the “Good” Death”, 43.

³⁶ Farr A. Curlin, “Hospice and Palliative Medicine’s Attempt at an Art of Dying”, *Dying in the Twenty-First Century*, ed. Lydia S. Dugdale (Cambridge; London: The MIT Press, 2015), 49.

avowed way by a decision of the doctor and the hospital team.”³⁷ Therefore, medical and technological advances have made death less unpredictable, personal, and religious.

The emergence and growth of bioethics gave patients and their families to actively engage in end-of-life decisions through the principle of respect for autonomy.³⁸ However, as highlighted by the report of The Hastings Center, “stimulating false and unrealistic public hopes, and creating expectations about the transformative powers of medical progress that cannot be achieved” is a new problem of medicine resulting from the process of medicalization.³⁹ In this context, this unrealistic perception of medical power leads to people seeking all medical interventions until death, which does not prevent death but impacts the time of death. For instance, particular interventions, such as cardiopulmonary resuscitation and mechanical ventilation, directly affect the time of death. Therefore, under today’s medical opportunities, letting a patient die or prolonging her/his life for a certain period is possible.

2. Ethical Concerns

Even though the history of medical ethics goes back to the time of Hippocrates, the patient’s autonomy-oriented ethical approach largely emerged through the growth of bioethics. Traditional medicine was physician-driven and requested physicians’ benevolence without considering patients’ participation in decision-making. However, contemporary medicine focuses on the patient’s autonomy and regards the patient as a primary stakeholder in all patient-related issues, including end-of-life care.⁴⁰ Nevertheless, regarding end-of-life issues, some believe that healthcare professionals should prolong patients’ lives as long as possible at all costs by utilizing life-sustaining technologies. In contrast, others focus on scarce resources and question life-prolonging treatments in the scope of justice.⁴¹ In this context, the matters of where to die, how to die, and when to die can cause different ethical dilemmas that can be seen on personal, social, and national levels.

³⁷ Aries, *Western Attitudes Toward Death from the Middle Ages to the Present*, 88.

³⁸ Lo, *Resolving Ethical Dilemmas: A Guide for Clinicians*, 13.

³⁹ Daniel Callahan, “The Goals of Medicine-Setting New Priorities”, *Hastings Center Report* 26/6 (1996), 6.

⁴⁰ Beauchamp - Childress, *Principles of Biomedical Ethics*, 1, 214.

⁴¹ Daniel P. Sulmasy et al., “Eleanor Roosevelt’s Last Days: A Bioethical Case Study”, *The American Journal of Medicine* 128/4 (2015), 438.

2.1. Social Responsibility, Autonomy, and Justice

Studies show that people vastly prefer dying at home. For instance, the study conducted by Deniz Ulker in Turkey demonstrates that 71.8% of the participants expressed their wishes to die at home.⁴² Similarly, most of the severely ill patients in Canada favor dying at home.⁴³ Furthermore, an overwhelming majority of Americans with terminal diseases hope to die at home, but more than 70% of them die in a healthcare facility, either at a hospital, nursing home, or hospice facility.⁴⁴ According to Joan M. Teno et al., in 2009, 24.6% of Medicare beneficiaries in the United States died in acute care hospitals, 29.2% of the beneficiaries used an intensive care unit (ICU) in the last month of their lives, and 42.2% of them were using hospice care in the time of their death.⁴⁵ These numbers demonstrate that a principal wish of people, dying at home, is not met at the end of their lives. As Li Yiting et al. emphasize, this situation can be interpreted as “[a]dvances in medicine have the capacity to extend a life that is often burdened with poor emotional and social quality.”⁴⁶ In this context, the imbalance between dying people’s wishes and the place where they die represents a crucial familial, social, and ethical challenge. In other words, the issue of where to die does not merely encompass a medical aspect but also social and ethical components. The social dimension is related to the relationship and responsibility between parents and their children or among family members, whereas the ethical aspect is associated with the connection between the principle of respect for autonomy and the possibility of honoring the patient’s last wishes to die at home.

The financial facet of where to die is another essential matter impacting the principle of justice. In Canada, the 2014 Ontario Auditor General’s report illustrated that palliative care at home is the most cost-effective method, costing less than \$100 per day compared with \$460 in a hospice facility and \$1,100 per day in an acute-care hospital in the last month of patients.⁴⁷ The figures in the United States indicate that Medicare has to devote approximately 25% of its expenditures to only about 5% of the beneficiaries receiving end-of-

⁴² Deniz Ulker, *Personal Preferences of Older People’s Family Caregivers Regarding End of Life Decisions*, (Mugla: Mugla Sitki Kocman University, Master’s Thesis, 2016), viii-ix.

⁴³ The Canadian Cancer Society, *Right to Care: Palliative care for all Canadians*, (Canadian Cancer Society, 2016), 11.

⁴⁴ Merrick, “Death and Dying: The American Experience”, 219.

⁴⁵ Joan M. Teno et al., “Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009”, *JAMA* 309/5 (2013), 470.

⁴⁶ Yiting et al., “End-of-Life Care in China: A View from Beijing”, 34.

⁴⁷ The Canadian Cancer Society, *Right to Care: Palliative care for all Canadians*, 16.

life care in the last year of their lives.⁴⁸ Therefore, the utilization of hospitals and intensive care units as a part of end-of-life care might be assessed with Curling's words as "[t]he overuse of life-sustaining technology [that] absorbs time, energy, attention, and resources."⁴⁹ In this view, in light of the principle of justice, end-of-life care, particularly hospital based-care, raises a fundamental ethical debate on whether to provide terminally ill patients with solely palliative care or honor their demand for aggressive therapies.

As mentioned above, choosing 'comfort measures only' or asking for life-sustaining interventions also affects the matter of when to die. Before the discovery of life-sustaining technologies, reversing the cessation of cardiopulmonary functions was impossible. However, nowadays, life-sustaining technologies, such as cardiovascular resuscitation and mechanical ventilation, give healthcare professionals the ability to reverse life-threatening situations and restore and maintain patients' medical conditions. At that point, currently available life-sustaining treatments are decisive medical interventions that directly influence the issue of when to die and transform death from a natural end to "a technical phenomenon."⁵⁰ However, aggressive life-sustaining treatments sometimes refer to forcing the patient to remain alive without basic human functions.⁵¹ Furthermore, showing extraordinary effort to keep the dying person alive contains ethical concerns regarding the principle of justice because futile medical interventions not only induce harm to the patient but also uselessly and unduly exhaust limited healthcare resources. The principle of justice demands utilizing healthcare resources fairly among all individuals and populations and not wasting them through ineffective treatments.

2.2. Autonomy, Beneficence, and Non-maleficence

Beneficence and non-maleficence are two traditional principles of medical ethics. Beneficence is a moral statement that requires producing good for patients, while non-maleficence refers to not harming patients. Beneficence carries a positive characteristic that requests healthcare professionals actively behave in accordance with the patient's best interest under available medical opportunities, whereas non-maleficence necessitates

⁴⁸ Gawande, *Being Mortal: Medicine and What Matter in the End*, 153.

⁴⁹ Curlin, "Hospice and Palliative Medicine's Attempt at an Art of Dying", 50.

⁵⁰ Aries, *Western Attitudes Toward Death from the Middle Ages to the Present*, 88.

⁵¹ Callahan, "The Elderly and Dementia", 156.

healthcare professionals not inducing unduly and useless harm to the patient.⁵² On the other hand, autonomy focuses on the patient's autonomous preferences and prioritizes the patient's decision over the caregivers' decisions. In this view, the issue of how to die creates several arguments regarding autonomy, beneficence, and non-maleficence. Euthanasia, palliative sedation, and assisted suicide are some of these subjects bringing about many ethical, religious, and philosophical questions concerning the conflict between patients' demands for dying painlessly and the duty of healthcare professionals.⁵³

Additionally, the use or omission of life-sustaining technologies, the determination of decision-makers, and the conflicts between patients' best interests and surrogates' decisions cause many ethical and legal problems.⁵⁴ Despite all the medical and technological advances, Atul Gawande underlines physicians' limited power in dealing with human biology and states, "I have seen the damage we in medicine do when we fail to acknowledge that such power is finite and always will be."⁵⁵ However, the overuse of aggressive treatment is not only a problem resulting from patients' perception of the limitations of medical interventions but also a predicted matter intentionally overlooked by some healthcare professionals. According to Gawande, almost half of the oncologists confess that they provide patients with certain treatments from which they know the patient most likely will not benefit.⁵⁶ This statement exhibits that some life-sustaining or aggressive treatments produce no benefit to patients, but false hopes, waste of resources, and harm to patients. To some extent, this violates the principles of autonomy due to not accurately informing patients about the expected consequences; the principle of beneficence because of not providing patients with useful options, such as hospice care; and the principle of non-maleficence due to applying ineffective treatments, which may harm patients physically and psychologically.

Conclusion

Death was previously considered a natural, personal, and religious phenomenon by accepting its reality and inevitability. However, advances in medicine and life-sustaining technologies have allowed healthcare professionals to get involved in the dying process and

⁵² Beauchamp - Childress, *Principles of Biomedical Ethics*, 150-153, 202-206.

⁵³ Sulmasy et al., "Eleanor Roosevelt's Last Days: A Bioethical Case Study", 437-439.

⁵⁴ Merrick, "Death and Dying: The American Experience", 224-233.

⁵⁵ Gawande, *Being Mortal: Medicine and What Matter in the End*, 259.

⁵⁶ Gawande, *Being Mortal: Medicine and What Matter in the End*, 167-168.

play certain roles through life-sustaining support, which has caused people to attribute excessive power to medical interventions and put healthcare professionals in the role of playing God. The *Ars moriendi* represents the approach that interprets death from a religious perspective, whereas medicalized death refers to the standpoint that contemporary medicine can avert death. The shift from the *Ars moriendi* to medicalized death has not only significantly changed people's perception of death, the dying process, and the potential of medicine, but also has led to certain ethical and social challenges surrounding the issues of where to die, how to die, and when to die: whether to die at home or in a healthcare facility; whether to receive pain management care or aggressive treatment; and whether to be on comfort measures only or life-sustaining care. The implementation or omission of these with each option's possible medical benefits and risks and financial burdens to patients, families, and/or societies engenders particular consequences that may not be congruent with ethical principles. For example, dying in a healthcare facility, instead of at home, addresses the respect for autonomy-related concerns; aggressive treatments, instead of the quality of life at the end of life, point out the beneficence- and non-maleficence-related worries; and hospital-driven treatments, instead of palliative care, and the relevant costs indicate the justice-related issues. For this reason, even though it is reasonable to continue benefiting from medical and technological developments, we should avoid the overuse of these technologies, accept the certainty of death, and acknowledge the scarcity of resources.

However, establishing a balance between the utilization of medical technologies and quality of life at the end of life necessitates a change in the mindset of pertinent stakeholders. At that point, educating healthcare professionals, patients, and families about the limitations of medicine, the advantages of palliative care, and the importance of utilizing healthcare resources effectively can produce desirable outcomes. In particular, patients and their families should be properly and adequately informed that instead of aggressive treatments in healthcare institutions, providing patients with severe illnesses with home-based hospice care would increase their quality of life through medical care (pain management), allow them to spend their last days with their family members, give them the opportunity of receiving spiritual and emotional care, and prevent them from unduly consuming scarce healthcare resources. Besides these practical benefits, home-based hospice care has great potential to satisfy relevant ethical requirements by honoring patients' wishes to die at home, benefitting them through medical, spiritual, and emotional support, preventing them from the harm of aggressive treatments, and eschewing the waste of scarce healthcare resources.

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