

## Review

# Ethical Considerations in End-of-Life Decision Making: Balancing Autonomy and Beneficence

Amani Hussain Alshawaf<sup>1</sup>, Ashwaq Saad Alghamdi<sup>2</sup>, Abdulmohsen Abdulrahman Shaikh<sup>3</sup>, Mohammad Fuad Kabli<sup>4</sup>, Abdullah Obaid Binobaid<sup>5</sup>, Zahra Ali Alshabib<sup>1</sup>

<sup>1</sup> Department of Family Medicine, Al-Ahsa Health Cluster, Al Ahsa, Saudi Arabia

<sup>2</sup> Primary Health Care, Ministry of Health, Eastern Province, Saudi Arabia

<sup>3</sup> Haramain Railway Station HC, Medina Health Cluster, Medina, Saudi Arabia

<sup>4</sup> Department of Family Medicine, King Fahad Hospital, Medina, Saudi Arabia

<sup>5</sup> Department of Internal Medicine, Security Forces Hospital, Riyadh, Saudi Arabia

Correspondence should be addressed to **Amani Hussain Alshawaf**, Department of Family Medicine, Al-Ahsa Health Cluster, Al Ahsa, Saudi Arabia, email: [omnia722@hotmail.com](mailto:omnia722@hotmail.com)

Copyright © 2024 **Amani Hussain Alshawaf**, this is an open-access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Received: 01 October 2024, Reviewed: 18 October 2024, Accepted: 19 October 2024, Published: 20 October 2024.

## Abstract

Population aging has intensified the need for thoughtful end-of-life care, as the global demographic of those aged over 60 continues to rise. Modern medical advancements, while extending life through interventions like artificial nutrition and respiratory support, have also heightened the focus on end-of-life care. This care involves managing terminal illnesses, ensuring dignified death, and supporting families and caregivers. Ethical considerations are paramount in this context, as decisions about treatment limitations or continuation often fall on families, proxies, or physicians when patients cannot decide for themselves. Balancing autonomy patients' rights to make their own medical decisions with beneficence the duty to act in the patient's best interest poses significant challenges. This review synthesizes ethical issues in end-of-life decision-making, emphasizing the principles of autonomy and beneficence. It explores dilemmas surrounding advanced directives, resuscitation, and palliative care. It underscores the importance of adopting a compassionate approach that honors patient preferences while managing intricate treatment choices to enhance quality of life and reduce suffering.

**Keywords:** end-of-life care, ethical decision-making, autonomy, beneficence, palliative care

**Introduction**

Population aging has gained prominence in numerous countries, with a notable increase in the number of people over 60 in recent decades. This demographic shift brings new considerations not only about the passage of time but also about the experiences associated with old age, shaped by social, economic, biological, and psychological factors (1).

Modern medicine and advanced technologies have profoundly impacted life expectancies and the traditional understanding of death. Although modern treatments and technologies may not treat chronic illnesses, they can prolong life by providing supplementary support, such as artificial nutrition and respiratory aids (2, 3). This extension of life has heightened the importance of end-of-life care, which begins with the diagnosis of a terminal illness and continues through to ensuring a dignified death as per the patient's wishes, including the period of mourning that follows (3). While death is a natural aspect of life, many individuals approaching the end-of-life endure unnecessary suffering, which also affects their family members, close friends, and informal caregivers. These caregivers are crucial throughout the end-of-life journey, both before and after the passing of their loved ones (4).

After a terminal diagnosis, the families of dying patients frequently experience intense stress, which may manifest as anger, depression, interpersonal conflicts, and psychosomatic issues (5). Family members also serve as primary caregivers for the terminally ill, and they may experience feelings of hopelessness, anger, guilt, and powerlessness when they are unable to alleviate their loved one's suffering (4). From an ethical perspective, decisions about limiting treatment or continuing non-curative interventions should ideally be made by the patient. However, if the patient is no longer capable of making decisions, the responsibility falls to the family, proxy healthcare provider, or physician to determine appropriate care (5, 6). Family members, who may be overwhelmed by sadness, fear, and anxiety due to a loved one's terminal illness, can struggle with decision-making. Without clear

knowledge of the patient's preferences for end-of-life care, making appropriate choices becomes more challenging, exacerbating their anxiety and stress. Conflicts can arise when family members have differing views on care; some may insist on doing everything to prolong life, while others might prefer to limit treatment and leave decisions to medical staff. These disagreements can place physicians in a difficult position (4).

The goals of care for terminally ill patients involve alleviating suffering, optimizing quality of life until death, and providing comfort during the dying process. However, achieving these goals presents numerous challenges. Physicians, patients, and families must make complex decisions about treatment options, such as whether to employ medical technologies to extend life or to permit the natural dying process. These decisions often come with ethical dilemmas concerning end-of-life care (2, 3, 5).

**Methodology**

This study is based on a comprehensive literature search conducted on 11 August 2024, in the Medline and Cochrane databases, utilizing the medical topic headings (MeSH) and a combination of all available related terms, according to the database. To prevent missing any research, a manual search for publications was conducted through Google Scholar, using the reference lists of the previously listed papers as a starting point. We looked for valuable information in papers that discussed ethical considerations in end-of-life decision making balancing autonomy and beneficence. There were no restrictions on date, language, participant age, or type of publication.

**Discussion**

End-of-life care represents a deeply profound and sensitive area of healthcare, requiring a thoughtful and compassionate approach to ethical decision-making. Establishing a strong ethical framework is crucial for ensuring that decisions honour the patient's values and wishes, while fostering dignity, respect, and a comprehensive approach to care (7).

***Autonomy***

The principle of autonomy, derived from the Greek word's *autos* (meaning "self") and *nomos* (meaning "rule"), represents the right of individuals to make their own decisions without external interference (8). Respecting self-determination is a fundamental aspect of modern medical practice, challenging traditional medical paternalism (9, 10). Competent patients have the right to be involved in their own healthcare planning, make choices regarding medical treatments or procedures, and express their preferences through advanced healthcare directives, which should be honored if they become incapacitated. However, there are situations where patients may not receive all the treatments they request. Since the introduction of cardiopulmonary resuscitation (CPR) in 1960, the application of the principle of autonomy has become especially pertinent in emergency care. Although CPR outcomes have continually improved (11, 12), many patients with terminal illnesses still die in hospitals, with cardiac arrest often marking the final stage of the dying process. CPR may delay a natural death, potentially conflicting with patient preferences (10).

Advance directives, also known as living wills, are documents in which individuals outline their preferences for medical procedures or interventions should they lose the ability to make decisions in the future. A durable power of attorney enables individuals to appoint trusted healthcare proxies, such as a relative or friend, to make treatment decisions on their behalf. These directives emphasize the right to consent to or refuse any medical treatment, including life-sustaining measures (9).

The concept of Do Not Attempt Resuscitation (DNAR) has been a contentious issue for a long time but is now acknowledged as representing either patient preferences or physician judgment (10). Improved education and information have empowered patients to make autonomous decisions regarding their health and end-of-life care (13). For a decision to be considered autonomous, the patient must have decisional capacity, adequate relevant information, and voluntarily disclose their choice.

Standard medical treatment and clinical research are distinct activities. However, patient autonomy can affect the feasibility of emergency clinical research, as informed consent (IC) is usually required for participation. In emergency situations, obtaining IC may not be possible due to time constraints. Ethical alternatives for respecting autonomy in emergency research include exception from informed consent with prior community consultation, prospective informed consent, integrated clinical informed consent, consent from a professional legal representative, and deferred informed consent (10).

***Beneficence***

The principle of beneficence involves selecting interventions based on an evaluation of their relative risks and benefits to the patient (14). For instance, the benefit of CPR is clear, as failure to resuscitate leads to irreversible death. However, there are exceptions for patients for whom cardiac arrest signifies the final stage of an irreversible illness and resuscitation would be undesirable. In most cases, CPR remains the primary method to restore spontaneous circulation and extend survival. Recent data indicates that an increasing number of patients are surviving both hospital admission and discharge (11, 12, 15).

The success of resuscitation is often evaluated based on whether the patient is cognitively intact and reports an "acceptable quality of life" or shows no significant deterioration from their pre-morbid state (14, 16). Historically, outcome assessments have largely depended on clinical evaluations using tools such as the Cerebral Performance Categories (CPC) or the Glasgow Outcome Scale (GOS), which often do not fully capture patient perspectives (17). Long-term outcome evaluations following hospital discharge are also infrequent (10). There is increasing awareness of the limitations of short-term, clinician-based assessments, which may overlook disability and cognitive impairment, and the differences between clinician, patient, and family perspectives on what constitutes a favorable outcome (17, 18). Updated international guidelines for cardiac arrest registries and recent core outcome set recommendations for cardiac arrest clinical trials now emphasize the importance of incorporating

survivors' perspectives in both short-term and long-term assessments (10).

**Decision-Making During End-of-Life Care**

In end-of-life care, the decision to either implement life-prolonging measures or focus on comfort can be challenging for physicians, patients, family members, or healthcare proxies (Table 1) (4).

**Making Ethical Decisions in Various Healthcare Settings**

Making ethical decisions in end-of-life care can differ greatly depending on the healthcare setting, each presenting its own challenges and requiring specific approaches. In Emergency Departments (EDs), the focus is often on stabilizing terminally and seriously ill patients and directing them to suitable services, rather than providing a dignified end-of-life process (19, 20). Family members may bring dying patients to an ED when they feel unable

to manage the end-of-life process at home. Due to the high-pressure, fast-paced nature of EDs, decisions must be made rapidly, often with limited information and time. Emergency physicians encounter ethical dilemmas, particularly regarding whether to perform resuscitation or continue life-sustaining treatments for patients who cannot make decisions themselves. According to guidelines from the Royal College of Emergency Medicine, the best treatment option should maximize general benefit and minimize future restrictions for the patient, with family involvement in decision-making wherever possible. When a patient is incapacitated, decisions are guided by advance directives (ADs) or designated health care proxies; in their absence, family members make these decisions. Disagreements between physicians and family members may require intervention from ethics committees or legal authorities (4).

Table 1. Major Challenges in End-of-Life Care Decision-Making (4)

Area	Considerations
<b>Cardiopulmonary Resuscitation (CPR)</b>	CPR may not be suitable for terminally ill patients. Factors to consider include patient preferences, success rates, risks, and benefits. DNR orders should be honored if the patient is competent.
<b>Mechanical Ventilation (MV), ECMO, and MCS</b>	These are used for comfort rather than extending life. Decisions to discontinue should be based on patient goals and effectiveness. The timing of removal should involve the patient's family.
<b>Artificial Nutrition and Hydration (ANH)</b>	ANH may fulfil basic needs but can also pose risks like aspiration pneumonia and gastrointestinal discomfort. Decisions should be made considering benefits and potential harms. ANH can be refused by competent patients.
<b>Terminal Sedation</b>	Used to alleviate severe suffering when other treatments fail. Criteria include terminal illness, unresponsive symptoms, and expected death within hours to days.
<b>Withholding and Withdrawing Treatment</b>	Withholding involves not starting interventions, while withdrawing means stopping ongoing treatments. Both require careful consideration of patient preferences and outcomes.
<b>Euthanasia and Physician-Assisted Suicide (PAS)</b>	Involves legal and ethical debates about the right to end life in certain circumstances.

In paediatric EDs, decision-making is further complicated by the patient's age and medical condition, which often limit their decision-making

capacity. Decisions are guided by the child's best interests, taking into account the benefits, burdens, and risks associated with treatment. Disagreements

between physicians and guardians can be addressed by ethics committees or, if necessary, the courts. Ethical dilemmas in paediatric care may involve decisions about pain management and the administration of narcotics, which can be mitigated through clear communication and education. Parents are expected to act in their child's best interests, but if their decisions are deemed harmful, physicians can seek support from ethics committees or the court system (21, 22).

Elderly patients often face end-of-life care decisions due to chronic, life-limiting conditions or cognitive impairments like dementia. Ethical decision-making in this context involves balancing the principles of nonmaleficence, beneficence, autonomy, and justice to improve the patient's quality of life and ensure a dignified end-of-life experience. Physicians should discuss care goals with patients and their family surrogates, encouraging advanced care planning and considering patients' preferences for end-of-life care (4).

Intensive Care Units (ICUs) present their own set of ethical challenges. Physicians must differentiate between patients who are treatable and those who are terminally ill. Once immediate issues are managed, the patient's care plan should be reassessed, ideally involving a shared decision-making model where both physicians and patients or their proxies participate. Empowering families and patients to make informed decisions is essential, and the principle of autonomy underpins the legal requirement for informed consent. When patients are unable to make decisions, ADs or proxies guide the process. If such documents are lacking, family members step in to make decisions, potentially leading to conflicts that may require ethical consultations or family meetings. Research indicates that ethical consultations can aid in resolving conflicts and guiding decision-making in complex situations (4).

### ***Hospice and palliative care***

Hospice and palliative care are essential aspects of end-of-life care, focusing on improving the quality of life for patients with terminal illnesses and their families. Although many individuals prefer to die at

home, various factors can complicate the delivery of high-quality end-of-life care in a home setting (23). In recent years, palliative care and hospice programs have developed to provide extensive support for terminal patients. The World Health Organization (WHO) defines palliative care as an approach aimed at enhancing the quality of life for patients and their families confronting life-threatening illnesses. This is accomplished through the prevention and alleviation of suffering by early identification, thorough assessment, and treatment of pain and other physical, psychosocial, and spiritual issues (4). Palliative care involves a multidisciplinary team of healthcare professionals. The Institute of Medicine (IOM) highlights the necessity for all physicians, regardless of their specialty, to have fundamental palliative care skills. These skills include patient-centered and family-oriented communication, professional collaboration, and effective symptom management (24).

Palliative care, including hospice care, aims to provide the highest quality of life for individuals with advanced serious illnesses or those nearing the end of life. Its main goal is to relieve suffering and improve quality of life for both patients and their families. Effective management of symptoms such as pain, shortness of breath, nausea, constipation, anorexia, insomnia, anxiety, depression, and confusion is crucial. These symptoms should be managed collaboratively with the patient and their family (4). Since psychological, spiritual, and social factors can affect symptom perception, it is essential to address psychosocial distress, spiritual concerns, and practical needs according to the preferences of patients and their families. In palliative care, the care plan is designed based on the goals of the patient and family, with regular reviews conducted by the multidisciplinary team (25).

Hospice care is a critical component of palliative care, concentrating on delivering comfort and support to patients with a limited life expectancy and their families. The primary goals of hospice care are to manage symptoms effectively and provide psychological and spiritual support during the final stages of life. Hospice care can be administered in various settings, including patients' homes, nursing

homes, hospitals, or specialized hospice facilities (25, 26). In addition to providing care for patients, hospice teams support primary caregivers and family members by offering emotional and spiritual support, social services, and nutrition counseling (4).

Research has shown that palliative care enhances quality of life, decreases acute healthcare utilization, and reduces symptom burden compared to standard care. Additionally, a meta-analysis of hospice care has indicated that it improves both quality of life and life expectancy for terminally ill patients (27). Therefore, healthcare providers caring for terminal patients should have fundamental palliative care skills, and hospice care should be included in health insurance coverage to ensure it is accessible to all patients. Ethical principles, particularly beneficence and nonmaleficence, are crucial in palliative care. Beneficence involves alleviating symptoms to enhance quality of life, while nonmaleficence emphasizes avoiding harm to the patient (26). Ethical decision-making in palliative care involves evaluating interventions such as CPR, mechanical ventilation, artificial nutrition and hydration, terminal sedation, and the withholding or withdrawal of treatments. These decisions are guided by ethical principles to ensure a comfortable end-of-life experience for patients (4).

### ***Future directions***

Future research should focus on enhancing communication strategies between patients, families, and healthcare providers to improve decision-making processes. Investigating the impact of personalized advance directives and incorporating patient preferences into end-of-life care more effectively are key areas. Additionally, exploring innovative palliative care models and integrating advanced technologies may optimize care delivery and support.

### **Conclusion**

Ethical end-of-life decision-making requires a delicate balance between respecting patient autonomy and ensuring beneficence. Effective care demands an understanding of these principles,

especially when patients are unable to communicate their wishes. A compassionate approach, guided by ethical considerations, is crucial for enhancing quality of life and minimizing suffering.

### **Disclosures**

#### ***Author Contributions***

The author has reviewed the final version to be published and agreed to be accountable for all aspects of the work.

#### ***Ethics Statement***

Not applicable

#### ***Consent for publications***

Not applicable

#### ***Data Availability***

All data is provided within the manuscript.

#### ***Conflict of interest***

The authors declare no competing interest.

#### ***Funding***

The author has declared that no financial support was received from any organization for the submitted work.

### **References**

1. de Oliveira S, Pacheco S, Nunes M, Caldas C, da Cunha A, Peres P. Bioethical aspects of health care provided to older adults at the end of their lives. *Revista Enfermagem*. 2020;28:1-9.
2. Karnik S, Kanekar A. Ethical Issues Surrounding End-of-Life Care: A Narrative Review. *Healthcare (Basel, Switzerland)*. 2016;4(2).
3. Thorns A. Ethical and legal issues in end-of-life care. *Clinical medicine (London, England)*. 2010;10(3):282-5.
4. Akdeniz M, Yardımcı B, Kavukcu E. Ethical considerations at the end-of-life care. *SAGE open medicine*. 2021;9:20503121211000918.
5. Crane MK, Wittink M, Doukas DJ. Respecting end-of-life treatment preferences. *American family physician*. 2005;72(7):1263-8.

6. Cavalieri TA. Ethical issues at the end of life. *The Journal of the American Osteopathic Association*. 2001;101(10):616-22.
7. Adnyana M. Ethical Considerations in AI-assisted Decision-Making for End-Of-Life Care in Healthcare. 2023
8. Mentzelopoulos SD, Mantzanas M, van Belle G, Nichol G. Evolution of European Union legislation on emergency research. *Resuscitation*. 2015;91:84-91.
9. Andorno R, Biller-Andorno N, Brauer S. Advance health care directives: towards a coordinated European policy? *European journal of health law*. 2009;16(3):207-27.
10. Mentzelopoulos SD, Haywood K, Cariou A, Mantzanas M, Bossaert L. Evolution of medical ethics in resuscitation and end of life. *Trends in Anaesthesia and Critical Care*. 2016;10:7-14.
11. Daya MR, Schmicker RH, Zive DM, Rea TD, Nichol G, Buick JE, et al. Out-of-hospital cardiac arrest survival improving over time: Results from the Resuscitation Outcomes Consortium (ROC). *Resuscitation*. 2015;91:108-15.
12. Girotra S, Cram P, Spertus JA, Nallamothu BK, Li Y, Jones PG, et al. Hospital variation in survival trends for in-hospital cardiac arrest. *Journal of the American Heart Association*. 2014;3(3):e000871.
13. Skulason B, Hauksdottir A, Ahcic K, Helgason AR. Death talk: gender differences in talking about one's own impending death. *BMC palliative care*. 2014;13(1):8.
14. Bossaert LL, Perkins GD, Askitopoulou H, Raffay VI, Greif R, Haywood KL, et al. European Resuscitation Council Guidelines for Resuscitation 2015: Section 11. The ethics of resuscitation and end-of-life decisions. *Resuscitation*. 2015;95:302-11.
15. Wissenberg M, Lippert FK, Folke F, Weeke P, Hansen CM, Christensen EF, et al. Association of national initiatives to improve cardiac arrest management with rates of bystander intervention and patient survival after out-of-hospital cardiac arrest. *Jama*. 2013;310(13):1377-84.
16. Beesems SG, Wittebrood KM, de Haan RJ, Koster RW. Cognitive function and quality of life after successful resuscitation from cardiac arrest. *Resuscitation*. 2014;85(9):1269-74.
17. Whitehead L, Perkins GD, Clarey A, Haywood KL. A systematic review of the outcomes reported in cardiac arrest clinical trials: the need for a core outcome set. *Resuscitation*. 2015;88:150-7.
18. Mak M, Moulaert VR, Pijls RW, Verbunt JA. Measuring outcome after cardiac arrest: construct validity of Cerebral Performance Category. *Resuscitation*. 2016;100:6-10.
19. Savory EA, Marco CA. End-of-life issues in the acute and critically ill patient. *Scandinavian journal of trauma, resuscitation and emergency medicine*. 2009;17:21.
20. Forero R, McDonnell G, Gallego B, McCarthy S, Mohsin M, Shanley C, et al. A Literature Review on Care at the End-of-Life in the Emergency Department. *Emergency medicine international*. 2012;2012:486516.
21. Cook I, Kirkup AL, Langham LJ, Malik MA, Marlow G, Sammy I. End of Life Care and Do Not Resuscitate Orders: How Much Does Age Influence Decision Making? A Systematic Review and Meta-Analysis. *Gerontology & geriatric medicine*. 2017;3:2333721417713422.
22. Santoro JD, Bennett M. Ethics of End of Life Decisions in Pediatrics: A Narrative Review of the Roles of Caregivers, Shared Decision-Making, and Patient Centered Values. *Behavioral sciences (Basel, Switzerland)*. 2018;8(5).
23. Sheehan DK, Schirm V. End-of-life care of older adults. *The American journal of nursing*. 2003;103(11):48-51, 4-8; quiz 9.
24. Committee on Approaching Death: Addressing Key End of Life I, Institute of M. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington (DC): National Academies Press (US)

Copyright 2015 by the National Academy of Sciences. All rights reserved.; 2015.

25. Barker P. Ethical dilemmas in palliative care. *InnovAiT*. 2017;10(8):489-92.

26. Elshamy K. Cultural and Ethical Challenges in Providing Palliative Care for Cancer Patients at the End-of-Life. *Palliative Medicine and Hospice Care - Open Journal*. 2017;SE:S75-S84.

27. Eichelberger T, Shadiack A. Life Expectancy with Hospice Care. *American family physician*. 2018;97(5):Online.