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Ethical considerations at the end-of-life care

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Abstract

The goal of end-of-life care for dying patients is to prevent or relieve suffering as much as possible while respecting the patients' desires. However, physicians face many ethical challenges in end-of-life care. Since the decisions to be made may concern patients' family members and society as well as the patients, it is important to protect the rights, dignity, and vigor of all parties involved in the clinical ethical decision-making process. Understanding the principles underlying biomedical ethics is important for physicians to solve the problems they face in end-of-life care. The main situations that create ethical difficulties for healthcare professionals are the decisions regarding resuscitation, mechanical ventilation, artificial nutrition and hydration, terminal sedation, withholding and withdrawing treatments, euthanasia, and physician-assisted suicide. Five ethical principles guide healthcare professionals in the management of these situations.

Keywords

End-of-life care, ethics, advance directives, ethical dilemmas, decision-making

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Introduction

Advances in modern medicine and medical technologies have both prolonged life expectancies and changed the natural norms of death. Although many modern treatments and technologies do not cure chronic diseases, medical interventions such as artificial nutrition and respiratory support can prolong the lives of people by providing secondary support.[1,2] End-of-life care has become an increasingly important topic in modern medical practice. This process starts with the diagnosis of a fatal disease, and includes the dignity death that the patient desires and the post-death mourning period.[2] Death is an inevitable part of life. Many people at the end of life experience unnecessary difficulty and suffering. Patients' family members, close friends and informal caregivers also experience a range of problems. They play very important roles in the end-of-life care of their loved ones before, during, and after death.[3]

After hearing about a terminal diagnosis, the families of dying patients experience a period of high stress that can be manifested by anger, depression, interpersonal conflict, and psychosomatic problems.[3,4] Family members are also primer caregivers for the dying patient. They may feel hopelessness, anger, guilt, and powerlessness when they cannot relieve the suffering of their terminally ill family member.[4]

From an ethical perspective, the patient rather than the family, proxy or physician makes decisions best about limiting treatment or treatments that do not provide cures but prolong life for a while. However, if the patient has lost the ability to make decisions, the family, the proxy health care or the physician must make a decision about the care to be provided to the patient.[4,5] Family members who feel sadness, fear, anxiety, and are stressed out because a loved one is terminally ill will have a hard time to make decisions. If they do not know their loved one's preferences regarding end-of-life care, they cannot be sure about whether they can give the most appropriate decisions for the patient. This can increase the anxiety and stress of family members. Sometimes family members may have different preferences regarding the care. While some family members clearly and unambivalently want that "everything" is done to keep their loved one alive, others are unable to decide to limit treatment and may want the medical staff to make these decisions for them. In such a situation, the physicians will be in a difficult situation.[3–6]

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The goals of care for terminally ill patients are the alleviation of suffering, the optimization of quality of life until death occurs, and the provision of comfort in death. However, achieving these goals is not always easy. Because physicians, patients, and patients' family members have to make decisions regarding treatment options such as whether to prolong a person's life with the support of medical technologies or allow the natural death process to continue, they face various ethical dilemmas related to end-of-life care.[1–4] Understanding the principles underlying biomedical ethics is important for physicians and their patients to solve the problems they face in end-of-life care. The ethical principles are autonomy, beneficence, nonmaleficence, fidelity, and justice.[5,6]

In this article, considerations regarding the application of ethical principles during end-of-life care are discussed.

Universal ethical principles

The ethical principles recognized universal are autonomy, beneficence, nonmaleficence, and justice. These "four principles" are common in Eastern and Western cultures, but their application and weight may differ. This article highlights the universally accepted features of these principles. The social and legal aspects that may affect the ethical principles in different cultures can be covered as a separate article.

Autonomy is considered a patient's right to self-determination. Everyone has the right to decide what kind of care they should receive and to have those decisions respected. Respecting patient autonomy is one of the fundamental principles of medical ethics.[4,6] This principle emphasizes physicians' protection of their patients' right to self-determination, even for patients who have lost the ability to make decisions. This protection can be achieved by using advance directives (ADs) appropriately.[4,6]

ADs are derived from the ethical principles of patient autonomy. They are oral and/or written instructions about the future medical care of a patient in the event he or she becomes unable to communicate, and loses the ability to make decisions for any reason. ADs completed by competent person ordinarily include living wills, health care proxies, and "do not resuscitate" (DNR) orders.[3,4,7,8] A living will is a written document in which a competent person provides instructions regarding health care preferences, and his or her preferences for medical interventions such as feeding tubes that can be applied to him or her in end-of-life care. A patient's living will take effect when the patient loses his or her decision-making abilities. A health care proxy (also called health care agent or power of attorney for health care) is the person appointed by the patient to make decisions on the patient's behalf when he or she loses the ability to make decision. A health care proxy is considered the legal representative of the patient in a situation of severe medical impairment.[4,7,8] The responsibility of the healthcare proxy is to decide what the patient would want, not what the proxy wants.[7,9]

Up until age 18, the patient's parents or legal guardians usually serve as their health care proxy. After the age of 18, they can legally appoint their own health care proxy. The proxies may be one of the family members or friends or another person. The proxies make decision about treatments, procedures, and life support. Even if their own wishes are different from the patient, the proxies must take into account the patient's possible preferences, not their own or anyone else, when making decisions on behalf of the patient.[7,8,10]

At the end of life, the priority of making decisions belongs to the patient. If the patient has lost the ability to make decisions, decisions are made according to the patient's AD, if any. The proxy health care is second in decision-making on behalf of the patient. If no AD or proxy, the decision-making is up to the family members. If family members avoid making decisions, the healthcare team must make a decision.[7,8,10]

ADs help ensure that patients receive the care they want and guide the patients' family members in dealing with the decision-making burden. Another reason for ADs is to limit the use of expensive, invasive, and useless care not requested by patients. Researches show that ADs improve the quality of end-of-life care and reduce the burden of care without increasing mortality.[7,11]

In many countries, the right of people to self-determination is a legal guarantee. Each patient's "right to self-determination" requires informed consent in terms of medical intervention and treatment. A patient has both the "right to demand the termination of treatment" (e.g. the discontinuation of life support) and the "right to refuse treatment altogether"; the exercise of these rights is strictly dependent on the person.[4,5] AD can be updated yearly and/or prior to any hospitalization.[9]

In many countries, the right of competent individuals to express their treatment preferences autonomously in end-of-life care should be met with ethical respect, taking into account the use of advanced treatments and the prognosis of their disease. However, this autonomy has some limitations. The decisions made by a patient should not harm him or her. It is important for healthcare providers to respect the autonomy of their patient and fulfill their duties to benefit their patients without harming them.[1–5,9]

Beneficence requires physicians to defend the most useful intervention for a given patient. Often, patients' wishes about end-of-life care are not expressed through ADs, and the patients' health care providers and family members may not be aware of their wishes about end-of-life care.[2,9,10] If a patient is not capable of decision-making, or if the patient has not previously documented his or her wishes in the event he or she becomes terminally ill, the end-of-life decision is made by the patient's physician as a result of consultations with the patient or the patient's relatives or the patient's health care proxy.[3–6] In this situation, the responsibility of the physician in the care of the dying patient should be to advocate the approaches that encourage the delivery of the best care available to the patient.[3]

Nonmaleficence is the principle of refraining from causing unnecessary harm. This principle concerns a basic maxim of good medical care: *Primum non nocere* (i.e. first, do no harm). Although some of the medical interventions might cause pain or some harm, nonmaleficence refers to the moral justification behind why the harm is caused. Harm can be justified if the benefit of the medical intervention is greater than the harm to the patient and the intervention is not intended to harm the patient.[5–7,12]

To comply with these principles of beneficence and nonmaleficence, healthcare professionals need to know their roles and responsibilities in end-of-life care.[4,5]

The ethical principle of justice is about ensuring a fair distribution of health resources and requires impartiality in the delivery of health services.[5–7,12] Medical resources are often limited and should, therefore, be distributed fairly and equally. There is already a need to evaluate the allocation of advanced medical therapy to avoid unnecessary use of limited resources. Healthcare providers have an ethical obligation to advocate for fair and appropriate treatment of patients at the end of life. This can be achieved through good education and knowledge of improved treatment outcomes.[4–7]

Fidelity principle requires physicians to be honest with their dying patient about the patients' prognosis and possible consequences of patients' disease.[5–7,12] Truth telling is fundamental to respecting autonomy. Most patients want to have full knowledge of their disease and its possible consequences, but this desire may decrease as they approach the end of their life. Some patients may not want information about their disease.[2,5] Physicians should be skilled in determining their patients' preferences for information and, honestly yet sensitively, provide their patients with as much accurate information as the patients want. Having effective patient-centered communication skills helps physicians learn and meet the demands of their patients.[5,13]

Healthcare professionals, especially physicians, should provide all the information about their patients' condition when appropriate. They have a duty to provide detailed information to patients and, if necessary, to the patients' decision-makers about advanced medical treatments that can be used during end-of-life care.[4,13] They can perform their duties by providing their patients with detailed information about the benefits, limitations, and disadvantages of these treatments. Even if a patient has the autonomy to choose his or her treatment, the physician should explain the results of all therapeutic interventions.[2–5] If the patient insists on a treatment that will not be beneficial or will or just prolong her or his life, the physician can withdraw from the patient's care by explaining why the treatment will not benefit the patient, the possible damage the physician may cause to the patient, and how the provision of the treatment will lead to the unnecessary use of resources. The physician also has the duty to protect the patient's life, but this task should not be confused with the use of unnecessary resources, and the patient should not be injured further by continuing useless or futile medical treatments.[1,4,5] In other cases, the benefit to the patients is determined only on the basis of the patients' subjective judgment of well-being. Medically futile treatments and interventions are those that are highly unlikely to benefit the patient.[9]

Medical futility is defined as a clinical action serving no useful purpose in attaining a specified goal for a given patient.[14] Futile medical care is care provided to a patient, although there is no hope of any benefit to the patient.[4] As a general rule, patients should be involved in deciding whether care is futile. In rare cases, it may not be favorable for the patients to participate in this discussion.[2,9] Futile and expensive treatments in end-of-life care increase the cost of healthcare and promote inequality in healthcare. Advanced technologies do not promise cures. The use of these technologies can sometimes harm the patient rather than benefit. Therefore, physicians should certainly consider the ethical value of the autonomy of their patients or his or her patients' proxies, but they should also discuss possible damage from treatments, and how the use of unnecessary resources leads to an increase in healthcare costs. Physicians do not have to apply to useless or futile treatment to patients.[3,9,10,14]

Decision-making during end-of-life care

In the end-of-life care of a patient, the decision to implement practices to prolong the patient's life or to comfort the patient may be difficult for the physician, patient, family members, or health care proxy. The following topics relate to some situations where difficulty in decision-making regarding end-of-life care is encountered:[9]

1. Cardiopulmonary resuscitation (CPR);
2. Mechanical ventilation (MV), extracorporeal membrane oxygenation (ECMO), and mechanical circulatory support (MCS);
3. Artificial nutrition and hydration (ANH);
4. Terminal sedation;
5. Withholding and withdrawing treatment;
6. Euthanasia and physician-assisted suicide (PAS).

Although CPR is valuable in the treatment of heart attacks and trauma, sometimes the use of CPR may not be appropriate for dying patients and may lead to complications and worsen the patients' quality of life. For some terminally ill patients, CPR is an undesired intervention. The decision not to perform CPR on a dying patient can be difficult for healthcare personnel. The decision to administer CPR to a patient depends on many factors such as patient preferences, the estimated success rate, the risks of the procedure, and the perceived benefit.[4,12,15] A competent patient may not want to undergo CPR in the event of cardiopulmonary arrest. This decision is called the DNR decision. Despite this request, the patient's family members may ask the physician to perform CPR. In this case, if the patient is conscious and has the ability to make decisions, the patient's decision is taken into account. Physicians must learn the CPR demands of patients at risk of cardiopulmonary arrest. DNR decision can be considered for the following patients:[9,10,15,16]

- Patients who may not benefit from CPR;
- Patients for whom CPR will cause permanent damage or loss of consciousness;
- Patients with poor quality of life who are unlikely to recover after CPR.

Approximately 75% of dying patients experience difficulty breathing or dyspnea. This feeling can be scary for patients and those who witness it. In end-of-life care, mechanical ventilation is applied not to prolong the lives of patients but to reduce their anxiety and to allow them to sleep better and eat more comfortably.[4,9]

MV, ECMO, and MCS are supportive therapies.[17–20] The decisions to deactivate these devices are made in a similar way. The principle of autonomy is pivotal in evaluating the refusal of treatment and the permissibility of life-ending interventions. If MV, ECMO, or MCS support does not provide any benefit to the patient or no longer meets its intended goals, or if the outcome is not optimal, or the quality of life is not acceptable according to the patient's or family's wishes, support can be terminated. The timing of the device separation should be chosen by the patient's family members.[17–20]

Nutrition and hydration are essential parts of human flourishing. ANH involves giving food and water to patients who are unconscious or unable to swallow.[9,21,22]

Artificial nutrition can be given through enteral feeding by tube or parenteral feeding. Nutrition and hydration decisions are among the most emotionally and ethically challenging decisions in end-of-life care. Many medical associations suggest that feeding and hydration treatments are forms of palliative care that meet basic human needs and must be given to patients at the end of life.[9,12,16,23] In 1990, the US Supreme Court noted that ANH is not different from other life-sustaining treatments. Although to do so speeds up death, competent adults may refuse artificial nutrition and hydration. ANH may improve the survival and quality of life of some patients such as extreme short bowel syndrome, bulbar amyotrophic lateral sclerosis, and in the acute phase of some disease such as stroke or head injury. It may improve the nutritional status of patients with nutritional problems. However, the evidence for the benefits of ANH is insufficient. ANH is associated with considerable risks such as the aspiration pneumonia, diarrhea, and gastrointestinal discomfort.[23,24]

In patients with advanced cancer, dehydration can cause symptoms such as fatigue, myoclonus, and delirium that impair quality of life, and sedation or agitation due to accumulation of active metabolites of opioids. However, the benefit of parenteral hydration in these patients is controversial. In a randomized controlled study, Bruera et al.[25] investigated the effect of parenteral hydration on quality of life and survival in cancer patients receiving hospice care. It was found that hydration at 1 L per day did not improve symptoms, quality of life, or survival compared with placebo. Johnston et al. conducted a study to determine factors associated with death after the percutaneous endoscopic gastrostomy (PEG) tube was inserted. In the study, 43% of the patients died within a week. Of these patients, 70% died because of respiratory disease. The expert panel considered that PEG tube insertion is futile in only 19% of the patients.[26]

For these reasons, the benefits and possible harms of the intervention should be explained to the patient or to the other decision-makers in detail before making the ANH decision. If a patient is incompetent, his or her proxy decision-maker can refuse artificial feeding and hydration on behalf of the patient.[9,21–23]

Terminal sedation is a medical intervention used in patients at the end of life, usually as a last effort to relieve suffering when death is inevitable. Sedatives are used for terminal sedation.[5,9] People have some concerns about terminal sedation because the treatment of an unconscious patient is sensitive and risky. The purpose of terminal sedation is not to cause or accelerate death but to alleviate pain that is unresponsive to other means. There are four criteria for evaluating a patient for terminal sedation.[5,9] According to the Center for Bioethics at the University of Minnesota, four criteria are required for a patient to be considered for terminal sedation.[5,9]

1. The patient has a terminal illness.
2. Severe symptoms are present, the symptoms are not responsive to treatment, and the symptoms are intolerable to the patient.
3. A "do not resuscitate" order is in effect.
4. Death is imminent (hours to days).

Some medical interventions in end-of-life care can save or prolong a patient's life. However, patients and their family members are often faced with decisions about when and if these treatments should be used or if the treatments should be withdrawn.[2,9] The terms withholding and withdrawing can be confused with each other. Withdrawing is a term used to mean that a life-sustaining intervention presently being given is stopped. Withholding is a term used to mean that life-sustaining treatment is not initiated or increased.[21,22]

The decision to withhold or withdraw interventions or treatment is one of the difficult decisions in end-of-life care that causes ethical dilemmas. If a patient and physician agree that there is no benefit in continuing an intervention, the right action is withholding or withdrawing the interventions. However, the physician must be skilled to manage this discussion sensitively. For this, physicians must have patient-centered and family-oriented communication skills. Respect for the autonomy of a patient seeking to continue or initiate treatment should be questioned when it would lead to enormous harm, the unnecessary or unequal distribution of resources, or action requiring the physician to act illegally.[23] In most countries, the legal opinion is that patients cannot seek treatment that is not in their best interest and, that physicians should not strive to protect life at all costs. However, if there is doubt, the decision must be in favor of preserving life. All healthcare professionals should be able to define an ethical approach to making decisions about withholding and withdrawing treatment that takes into account the law, government guidance, evidentiary base, and available resources.[14,22,23,27]

Physicians must be aware of their patients' capacity, beliefs, and preferences, as well as their clinical condition.[2,9]

For many decades, euthanasia and PAS have been discussed in the context of terminal care in modern societies. The ethics and legality of euthanasia and PAS continue to be controversial.[28]

Euthanasia is applied in two ways as active or passive euthanasia. In active euthanasia, a person (generally a physician) administers a medication, such as a sedative and neuromuscular relaxant, to intentionally end a patient's life at the mentally competent patient's explicit request. Passive euthanasia occurs when a patient suffers from an incurable disease and decides not to apply life-prolonging treatments, such as artificial nutrition or hydration. In PAS or physician-assisted death, a physician provides medication or a prescription to a patient at patient's explicit request, with the understanding that the patient intends to use the medications to end his or her life.[28–30]

From a global perspective, there are countries (or states) where euthanasia and PAS are accepted and legal and others where they are still offenses. In countries where euthanasia and PAS are legal, a physician has the right to refuse a patient's request.[28]

At the present time, active euthanasia is legal in five countries (Belgium, the Netherlands, Luxemburg, Canada, and Colombia), although the laws of these countries differ considerably regarding practices. Passive euthanasia is legal in 12 countries (Belgium, the Netherlands, Luxemburg, Switzerland, Germany, Austria, Norway, Sweden, Spain, Canada, Colombia; and Mexico, Argentina, and Chile). PAS is legal in seven countries (Belgium, the Netherlands, Luxemburg, Switzerland, Germany, Finland, Canada, and Japan). In the United States, active euthanasia is illegal, but PAS is legal in 10 states (Oregon, Washington, Vermont, California, Colorado, Washington, DC, Hawaii, New Jersey, Maine, and Montana).[30–32] In countries other than Belgium and the Netherlands, the right to euthanasia applies to individuals aged 18 and older. There is no age limit for euthanasia requests in Belgium. In the Netherlands, people aged 12 and older who meet the necessary conditions can request euthanasia.[30,31]

Ethical decision-making in different healthcare settings

Different difficulties can be experienced when applying ethical principles in different healthcare settings where end-of-life care is provided.

Emergency departments (EDs) are settings where healthcare services are provided to terminally ill and seriously ill patients, as well as potentially treatable patients. The goal of healthcare services provided in EDs is to refer patients to an appropriate service after treating urgent problems and stabilizing the patients. EDs are not suitable environments in which to provide a dignified death process.[33,34] However, family members of dying patients can bring the patients to an ED when they feel incapable of managing the death process at home.[33]

In EDs, decisions often need to be made in a short time. Emergency physicians face numerous challenges when managing the clinical care of patients at the end of life. The most important ethical problem faced by emergency physicians in end-of-life care is making ethical decisions on issues such as whether to perform resuscitation and continue life-sustaining treatment in cases where the patients are not competent to make decisions.[33,34]

Emergency physicians aim to support life through all possible means unless an AD requests otherwise. The Royal College of Emergency Medicine published a best-practice guide for end-of-life care for adult patients in EDs. In the aforementioned guidelines, it is stated that "the best treatment option is the one that provides the most general benefit and is the least restrictive for the patient's future choices, and patients and their families should be involved, wherever possible, in end-of-life care decisions."[35]

If a patient is unable to make his or her own decisions about health care and has an AD or has appointed a health care proxy, the decisions are based on these documents. In cases where there is no AD or appointed health care proxy, family members must decide. Physicians and family members or health care proxies sometimes may not agree on medical decisions. In these cases, physicians should act according to the decision of ethics committees or the laws of the country.[34,35]

In pediatric EDs, most terminal patients lack decision-making capacity due to their age and medical condition. Decisions for a child should be made in the context of the child's best interests. A determination of "best interests" involves weighing the benefits, burdens, and risks of treatment to achieve the best possible outcome for the child or adolescent.[36–39]

In most countries such as the United States, United Kingdom, and Turkey, legal and medical decision-makers are the parents or legal guardians of the children. Generally, physicians and decision-makers on behalf of the child agree on end-of-life care decisions. However, sometimes there is conflict over decisions. If a child's physician thinks that the family or legal guardian's decision is not the best decision for the child, the physician can apply to ethics committees or courts.[36–39]

Most dying pediatric patients receive care in hospitals, often in pediatric ICUs. Decisions regarding the end-of-life care of children are made in accordance with ethical principles and the laws of the relevant country.[36,37]

Children under the age of 18 years are not legally considered competent to make that decision. However, in some countries such as the United States, pregnant women, married women, children living independently and away from their families, and financially independent children are considered to be able to make their own decisions. It is accepted that children above the age of 6 should be informed about decisions regarding their end-of-life care and that their preferences should be taken into account in the decision-making process, even if they cannot make their own care decisions.[35–39]

Pediatricians sometimes face ethical dilemmas and difficult decisions in the care of children at the end of life.[37,40] Often, parents agree with the advice of physicians. However, an ethical dilemma can arise when there is a disagreement about the care plan. Ethical dilemmas can arise in deciding whether to administer narcotics for the cessation and/or withdrawal of medical interventions and in decisions regarding the accuracy and administration of narcotics for pain and symptom management. Most difficult situations can be managed with effective communication within the medical team or between the team and the patient/family.[38] Providing families and children with clearly explained and understandable verbal and written information specific to the children's individual circumstances and their management can enable the families and children to better assess the situation. When difficult decisions need to be made about end-of-life care, giving children and their parents or legal guardians sufficient time and opportunities for discussions can also help resolve problems.[39–41]

Parental decisions are not absolute. In circumstances where a parent makes a decision that could potentially harm a child, the physician can seek assistance from the institution's ethics committee if the physician is concerned that the decision is not in the best interests of the child. Going to court can be an option of last resort when the medical team believes that a family's decisions are reaching the point of being harmful to the child.[15,37,38]

Elderly individuals represent the most rapidly growing segment of the population. Many chronic, life-limiting diseases such as advanced cancer, neurodegenerative diseases, and organ or system failure occur in elderly individuals. In addition, many elderly people have cognitive impairments such as dementia that affect decision-making.[42–44]

Several ethical issues arise in the care of elderly patients at the end of life. There is much common ground based on the application of the four major principles of medical ethics: nonmaleficence, beneficence, autonomy, and justice. The goal of end-of-life care for elderly people is to improve their quality of life, helping them cope with illness, disability, death, and an honorable death process. These goals should be achieved by considering these ethical principles.[41–44]

Physicians who provide care to elderly patients with a terminal illness should discuss the goals of care with the patients and family surrogate decision-makers. This discussion provides valuable information to the physicians and the patients' decision-makers about what kind of care the patients want to receive at the end of life and what kind of death they prefer. Physicians should be encouraged to advance life planning for their elderly patients.[4,41–44]

There are some features of ethical decision-making in ICUs. It is important for physicians working in ICUs to distinguish between treatable patients and those in the terminal period. In the care of a dying patient in an ICU, after the emergency situations are resolved, the patient's care should be reevaluated. In this planning, decisions are made for the next phase of care of the patient. Ideally, this decision-making process is a shared decision-making model in which the doctors and patient or the patient's proxy share information with each other and participate jointly in the decision-making process.[45–48]

It is very important to empower the family and, if possible, the patient to participate in this decision. The patient and his or her family members/care proxy should be assisted in making decisions through explanations of the patient's condition, possible interventions, and the results of those interventions in clear and understandable language. The ethical principle of autonomy supports the legal requirement for informed consent.[45–48]

Physicians working in ICUs may face ethical dilemmas in decision-making regarding end-of-life care. They should make end-of-life care decisions according to the basic ethical principles (autonomy, beneficence, nonmaleficence, and justice).[41] According to the autonomy principle, patients have decision-making priority. However, many critically ill patients in ICUs do not have the capacity to make decisions. In such cases, if the patients have an AD or health care proxy, decisions are made according to those documents. If there are no such documents, the decision-making falls on the patients' family members. When there are disagreements between family members, a family meeting can be helpful.[46–48]

Physicians sometimes think that the decisions made by family members are not the most appropriate decisions for the patients. In cases of conflict between intensive care teams and family members, assistance from institutional ethics committees may be sought.[48] In a study by Schneiderman et al.,[49] it was found that ethical consultations help resolve conflicts.

Palliative care and hospice care

Most people express a preference for dying at home.[50] However, various factors may make it impossible to deliver quality end-of-life care in the patient's home. In recent years, palliative care and hospice programs that provide care for terminal patients have gradually improved.

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[51]

Palliative care is given by an interdisciplinary team. In its report "Dying in America," the American Medical Institute (Institute of Medicine (IOM)) emphasizes that all physicians in disciplines and specialties that care for people with terminal disease should be competent in basic palliative care skills, such as person-centered and family-oriented communication skills, professional cooperation, and symptom management.[52]

Palliative care, including hospice, as an established approach providing the best possible quality of life for people of all ages who have an advanced serious illness or are likely approaching death. The main goal is to prevent and relieve suffering, to improve quality of life for both the patient and the family.[43,52] Control of symptoms such as pain, shortness of breath, nausea, constipation, anorexia, insomnia, anxiety, depression, and confusion should be addressed with the patient and family.[53,54]

Because psychological, spiritual, and social factors may all affect the perception of symptoms, psychosocial distress, spiritual issues, and practical needs should be handled appropriately according to the preferences of patients and their families.[55] In palliative care, the care plan is determined according to the goals of the patient and family with the guidance of the multidisciplinary health care team, and is regularly reviewed.[53,55]

Hospice is an essential approach to address the palliative care needs of patients with limited life expectancy and their families. Hospices are an important component of palliative care. Hospice care focuses primarily on symptom control and psychologic and spiritual support for dying patients and their families.[43,52] Hospice teams' goal is to make the patient as comfortable as possible in the end of life. Hospice can be provided in any setting, including patients' homes, nursing homes, hospitals, and a separate hospice facility.[55,56] In addition to patient care, the interdisciplinary team provides support to the primary caregiver or family member who is responsible for the majority of the patient care.[55,57] Hospice team may provide emotional and spiritual support, social services, nutrition counseling, and grief counseling for the patients and their families.

Studies have shown that palliative care results in improved quality of life with less acute health care use and in moderately lower symptom burden compared to routine care.[58] A meta-analysis on hospice care have also shown that hospice care increases the quality of life and life expectancy for terminal ill patients.[59] Therefore, health care providers who will care for terminal patients must have primary palliative care skills. In addition, for all patients to benefit, hospice care must be covered by health insurance in all countries.

All ethical principles should also be taken into account in palliative care delivery. However, the most considered ethical principles are beneficence and nonmaleficence. Beneficence emphasizes on relieving the symptoms that impair the quality of life of a dying person. Nonmaleficence emphasizes on relieving the symptoms that can actually harm the patient.[56]

In palliative care setting, the end-of-life decision mentioned above (CPR, MV, ANH, terminal sedation, withholding and withdrawing treatment) may need to be taken. The application of the ethical principles in palliative decision-making is required to achieve a comfortable end-of-life period for patients.[53,56]

Conclusion

The goal of end-of-life care is to prevent or relieve suffering as much as possible while respecting the desires of dying patients. However, physicians face many ethical challenges in end-of-life care. Since the decisions to be made may concern patients' family members and society as well as the patients, it is important to protect the rights, dignity, and vigor of all parties involved in the clinical ethical decision-making process. Open communication and shared decision-making among health care providers, patients, and families would avoid many of the ethical dilemmas at end-of-life care.

Limitations

There are different beliefs, traditions, and legal regulations that affect the application of ethical principles in different societies. This article discusses universal ethical principles accepted in end-of-life care; however, the application of ethical principles in different societies is not mentioned. In addition, the role of different healthcare professionals in end-of-life care has not been discussed.

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