Special Article

Ethical Decision-Making in the Care of the Dying and Its Applications to Clinical Practice

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Abstract
In caring for dying patients, physicians and health team members face a number of decisions about how best to proceed with treatment. Many of these decisions carry implications for the life of the patient, either directly or indirectly. Recent discussions about the morality and wisdom of euthanasia provide an excellent stimulus to reexamine the ethical nature of these decisions. This paper reviews five ethical principles, and describes a process of decision-making that can result in two broad paths of action in relation to life-prolonging treatment. Case examples are presented for illustration.


Key Words
Decision-making, dying, euthanasia, medical ethics

Introduction
The compelling challenge of determining appropriate and compassionate care for dying, irreversibly ill, or physically damaged patients continues to pose a problem for society. Life and death treatment issues have again been brought to prominence by recent controversial legal cases in the United States and information originating in the Netherlands, where euthanasia, although still illegal, is state-sanctioned and supported by professional policy and guidelines. The idea of ending the life of suffering persons is not new. Proposals or bills for its legalization have appeared repeatedly in this century, most recently in California, but have been defeated each time. Thus, euthanasia as the solution to the difficult treatment dilemmas posed by such patients does not seem to be something that society embraces. Wisely, the issues are seen to be much more complex.

Important questions emerge. What are the ethical issues in life and death decisions about treatment? How do certain practices differ? What are appropriate professional responsibilities to patients who suffer? How do current patient care practices involving symptom control (particularly pain relief) and treatment issues such as noninitiation or cessation of therapy differ from euthanasia?

Health professionals and society are urged to reflect on these issues very carefully. The increasing interest in euthanasia is occurring at a time when medicine is gingerly, yet bravely, trying to explore the practice of allowing people to die when that seems appropriate and in their best interest. New lines are being drawn between the morally acceptable and unacceptable.
Physicians, other health professionals and lay people alike, all of whom share a great desire to relieve patient suffering, may be confused about the ethical, moral, and legal basis and significance of actions that might be considered in various clinical situations.

In an attempt to clarify thinking about these issues, the relevant ethical principles that need to be understood to support or refute certain practices will be reviewed. A process for decision-making and the nature of the potential options for care that may result from various decisions will be discussed.

Relevant Ethical Principles

Four cardinal principles form the basis for an ethical consideration of treatment practices. These are autonomy, beneficence, nonmaleficence, and justice. There are also a number of rules and obligations that relate to the principles, and influence their implementation in clinical work. These include the obligation to tell the truth and to act in a trustworthy way in professional relationships with patients. A brief summary of the cardinal principles is presented here. The reader is directed to references for further consideration of these principles and rules, their relationship one to another, and their applications.3,5—10

Respect for Autonomy

Respect for autonomy recognizes an individual's right or ability to decide for himself, according to beliefs, values, and a life plan. As the cornerstone of ethical professional practice and the basis of physician—patient relationships, respect for autonomy in medical practice recognizes that patients' decisions are uniquely their own, and that these decisions may be opposite to the course that is advised or deemed wise in a given situation. Autonomy exists when patients act intentionally, with understanding, and without controlling influences. Respect for autonomy is the opposite of paternalism, which says "I know what is best for you."

Respect for autonomy relies upon truth-telling, the conveying of accurate information, and the determination that a patient understands the facts of the situation and the implications of decisions. It recognizes that the patient may value certain components of the situation differently than does the physician or health care team.

The patient is assumed to have the capacity to understand and make decisions unless there is real evidence to the contrary. Patients who are incompetent in one aspect of their lives, for example in managing financial affairs, may still have the capacity to understand clinical issues and to make decisions about their care.

Although very important, respect for autonomy is not the only principle to be considered in medical decision-making. It is not without limits. For example, the exercise of autonomy does not necessarily imply an obligation upon others to act. However, it is very compelling, because it is based in moral thought, cultural practice, and legal precedent.

Respect for autonomy is central to the care of dying patients. Dying is an important and universal personal human event, in which persons must be gently informed and thereby allowed to participate. Gentle truth-telling and exchange of accurate information about status, options, planned care, and future expectations is essential. The clinical challenge that this presents is the art of medicine.

Nonmaleficence

This principle is embodied in the concept "one ought not to inflict evil or harm." Causing unnecessary physical or psychological pain to patients while performing tests or procedures, or during history-taking, physical examination, or the conveying of information is a violation of the principle of nonmaleficence.Insensitive truth-telling (the "assault of truth") is a violation, as is any denigration of the individual person in the process of caring for him/her. Nonmaleficence admonishes against acts or behaviors that inflict harm. Nonmaleficence is also relevant to the dying. These patients are frail and vulnerable, and require a strong commitment that they will not come to harm through the care provided them. They must not be overtreated or undertreated. Continued aggressive life-prolonging or cure-oriented treatment that is not suited to their needs or wishes may be a violation of nonmaleficence. Unnecessary and unwanted oversedation or premature, unrequested, or uninformed withdrawal of treatment may be another.

Beneficence

This concept states that "one ought to prevent or remove evil or harm, and so or promote good." Beneficence implies positive acts and
includes all of the strategies that health care professionals employ to support patients and families and reduce suffering. This includes the effective treatment of pain and other symptoms, sensitive interpersonal support, and the acknowledgment of the patient as a unique human being to be respected and valued.

Various proposed treatments can be evaluated in terms of their potential to prevent or remove distressing symptoms or suffering, and thereby promote good. Cessation of treatment can in appropriate clinical context be viewed as an act of beneficence, where continued life is viewed by the patient as an “evil or harm.” Treatment plans that are in line with the goals of care that a patient sees for him/herself (Figure I) would convey beneficence.

**Justice**

Justice deals with the concept of fairness, “due,” or what is deserved by people. It describes what individuals are legitimately entitled to and what they can claim. At a societal level, justice reflects policy and the distribution of goods and services. For the individual, it may also serve to limit autonomy; what the individual wishes, chooses or feels entitled to may not be allowable in the context of the greater good. This may be regrettable, but necessary to maintain the particular values upon which society is based.

Decisions and actions that may seem morally compelling and appropriate for a particular person may not be allowable because of the wider risk they present to other members of society. Euthanasia may be one such action. On the contrary, seriously ill or dying people should not be deprived of certain therapies if they wish to attempt them and have full knowledge of what is entailed. Cardiopulmonary resuscitation of the patient with far-advanced cancer in the event of sudden cardiac arrest prior to the dying phase of illness may be an example of this.

Justice also demands that dying patients have access to care equal to others. Sadly, this has not always been the case, in that the dying patient may be viewed as less of a priority.

**Principle of Double Effect**

This principle is not one of the cardinal ethical principles, but rather is a metaethical or procedural principle utilized in helping to decide whether some evil effects can be accepted.

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**Fig. 1. Medical decision-making with dying patients.**
in an action. It applies to situations in which there is a difference between the intended effects and the nonintended, albeit foreseen effects of an action. To invoke this principle, intentions and motives must be evident, and the practitioner must clearly intend a desirable outcome while recognizing the possibility of other undesirable and unavoidable outcomes. The undesirable secondary effect must in no way be wished or planned as being the "true goal" of the action.

The most common clinical application of this principle arises in situations of intractable symptoms like pain or suffocation, where there is a compelling need to act in using opioid analgesics to realize the moral goal of patient relief. The physician may recognize the possible risk of a secondary effect, respiratory depression, that may shorten life, but does not primarily intend this. The risk of this undesirable outcome can be accepted only because of the more compelling need to act.

Medical Decision-Making in the Care of the Dying

Figure 1 illustrates an approach to decision-making for the dying patient. Consideration is given to the illness and to the patient's experience, goals, and plans. Goals of care are established jointly by patient and family together with the health care team. The process of decision-making undertaken by the physician and health team and an examination of the way in which they have considered the competing moral principles involved are as important as the decision reached.5–10

In this approach, various treatment options are considered in relation to their ability to enhance established goals. Once it has been decided whether prolongation of life is viewed as a paramount goal or not, two broad paths of care become evident (Figure 2). Full supportive care is necessary in both paths, but they vary in the types of treatments that are appropriate and the degree of risk that is acceptable as supportive therapies are undertaken. Renegotiation of goals should occur if the patient's condition changes significantly, either towards improvement or deterioration.

Noninitiation or Cessation of Treatment

Certain treatments or therapies should not be undertaken if they are unwanted or unwarranted. The competent patient is assumed to have the capacity for voluntary participation in
decision-making through the process of informed consent. Such a patient may decline to start a course of management on the basis of the information provided and previously held views, beliefs, and values (the exercise of autonomy). Where the patient is found to lack the capacity to act autonomously, proxy consent is sought. Usually this will be from family, who is seen to be in a position to know best what the patient’s wishes would be if he/she could make them known (patient’s expressed prior wishes).

If discussion with family is not sufficiently revealing of the patient’s wishes, then the concept of a “reasonable person” might be invoked. In this situation, the benefits and burdens of the proposed therapy or treatment are described, and clinicians, families, ethics committees, and sometimes courts attempt to determine what a reasonable person would choose to do. It is apparent that decision-making on behalf of the incompetent patient will remain one of the most controversial issues in this area, as the concepts of benefit and burden are weighed differently by various participants and this gives rise to vastly disparate views of what a “reasonable person” might choose.

There is also still considerable controversy over what constitutes treatment and what is simply supportive care to which everyone is entitled. This is particularly evidenced by the issues of withholding or not starting artificial feeding or hydration and the definition, in this context, of “artificial” itself.\(^6\)\(^7\)\(^8\)

Cessation of treatment, as opposed to noninitiation, must also be considered in each of two general contexts described above, that of the competent patient who requests that treatment be stopped, and the noncompetent patient who is unable to do so. Cessation of treatment, although sometimes more psychologically and emotionally problematic for professionals, patients, and families, is no different, ethically, than never having started it in the first place.\(^5\)\(^7\)\(^9\) In fact, treatment once started may at times be stopped with somewhat more confidence, because all parties have had an opportunity to assess more accurately the actual experienced benefits and burdens of therapy.

As with noninitiation of therapy, cessation of treatment is most problematic when it is considered for noncompetent patients, not only because it can be difficult to know what the patient might have wanted, but also because the onus of doing unto another is a burden shared by society as a whole. In this situation, motives and outcomes must be carefully and honestly considered.

**Continued Treatment**

Treatment is continued when it is consistent with the goals of care for the patient. Such goals are based on the status of the illness, the range of possible treatments and the patient’s wishes about them, and the benefits and burdens involved. Open negotiation before commencing a trial of therapy can allow for its cessation by mutual agreement if outcomes are not as expected. A course of therapy, once embarked upon, should not be considered irrevocable.

The ethical soundness of a particular decision can only be judged in the clinical context. For example, it would be ethically wrong to withhold potentially beneficial treatment from an incompetent patient if its benefits clearly outweighed its burdens and it was clear that this patient or a reasonable person would choose to have it. On the other hand, even the patient’s expressed refusal of treatment may sometimes be overruled, particularly if there is good reason to believe that the decision is not well informed or that the patient is not acting in a manner consistent with his or her own prior values, wishes, and life plan, or that he/she lacks capacity to decide.\(^12\)

Decisions made for or with one patient may not necessarily apply to another. Such decisions cannot be made categorically, on the basis of policies, protocols, or impersonal generalizations about age or diagnosis. Rather, they must be based on thoughtful analysis of the issues in a particular patient’s situation and a clear exchange of information among patient, family, and health professional team. Such an open examination of issues and the viewpoints of all will give a firmer ethical foundation upon which to decide and act.

**Necessary Actions that Increase the Risk of Death**

Treatments in this group have the potential for shortening life. They may be necessary either in the setting of continued treatment or the setting in which treatments are stopped or not
begun. They are considered under the principle of double effect above.

In essence, such decisions are morally and ethically defensible if there is a compelling need to act. In patients with advanced diseases, such need may exist in the treatment of intractable pain, suffocation, or choking, in which the compelling moral obligation is the relief of distress in accordance with the principle of beneficence. The physician acts with the knowledge of the potential risk for shortening life (in actual practice, the risk may be quite low), but does not primarily act to bring about death. Most important, the physician does not fail to act when the need exists, because the moral need to relieve suffering is recognized as being paramount.

Physicians, in collaboration with patient and family, should provide more definitive and effective treatment of these sorts of symptom crises when they occur. This would do much to relieve suffering and the anticipated fear of it. Such actions can be clearly distinguished from the primary intention to take life (euthanasia).

**Sound Treatment Decisions Versus Euthanasia**

It is important to recognize that well-taken decisions to cease or not start treatments in the care of dying patients are distinct from euthanasia. The distinction lies in the motivation or intention, which is to relieve the patient of treatments that are not wanted or are not of benefit. Death may occur if it is inevitable, from the disease process, because obstacles are removed or not placed in its way. Direct control over life and death is not taken, as it would be in euthanasia, where the goal is the death of the patient not the removal or avoidance of troublesome treatments.

To avoid confusion, the word euthanasia would be best limited to describe that pattern of practice that acts specifically with the goal to end life. It is not part of medical practice and represents a topic of considerable controversy.1–5,11,13–26

**Clinical Application**

The foregoing discussion can be applied to three clinical cases to illustrate ways to consider clinical dilemmas.

**Case 1**

A 54-yr-old woman who is quadriplegic and ventilator dependent, asks to have the ventilator removed so she can die. Her life, as she experiences it, is intolerable and her continued treatment too burdensome in her view.

**Case 2**

A 37-yr-old man dying of histiocytoma is paraplegic and has severe neuropathic pain that requires morphine 800 mg/hr, IV. He is alert and still experiences severe pain. Neurosurgical consultation for pain relief has been arranged, but, in the meantime, he requires increases in his opioid analgesic. Such action, although necessary, may shorten his life.

**Case 3**

A 34-yr-old woman with multiple sclerosis is unable to move. She can speak, but has choking spells. She is clearly suffering from her incapacity and asks that she be given something to help her die.

Continued treatment against the wishes of the autonomous patient in case 1 can be seen as a violation of the principles of respect for autonomy and nonmaleficence if continued ventilation is viewed as doing harm, and a violation of beneficence, if removal from the ventilator were seen as good. Alternately, one could define death as the greater harm and conclude that her continued ventilation was most beneficent and least harmful to her, although this would be difficult to defend because the necessity to preserve life at all costs is no longer seen as paramount.

The principle of respect for autonomy would be very compelling in case 1, as the continued treatment of a competent patient against his/her consistently expressed wishes to the contrary, which is occurring in the absence of modifiable factors like a clinical depression, is not ethically sound.5–9 The ventilator is seen as an impediment to her natural death. The intention in removing the ventilator is to allow death, if it is inevitable, by cessation of unwanted treatment.

Although the decision to remove a ventilator may be ethically sound, it cannot be taken lightly or in haste. In clinical practice, the management of such a case is extremely complicated10 and patients must be provided
ample opportunities to explore all options for a potentially more meaningful life. Adequate resources—physical and financial, imaginative and interpersonal—are necessary for them to do this.

Case 2 illustrates an application of the principle of double effect. This is true only if the physician's actions are motivated by the intention to relieve pain and not to kill the patient. The patient may die as a result of the necessary action (giving bolus doses of morphine), and although the possibility of shortened life is foreseen, death is not desired or intended. The fact that the patient's life may be shortened as a result of the action is a regrettable and unwished potential consequence that can be tolerated only because of the clear need to act (severe intractable pain). Indeed, were it not for the need to relieve the pain, the physician would not act. Were the clinician to wish, will, or intend the death of the patient by his or her actions, or were there no clear and compelling need to act, then the action could not be justified on the basis of the principle of double effect.

The woman in case 3 is asking the physician to take her life. Her physical and psychological situation is compelling. She is not asking for cessation of treatment, because in essence, there is nothing to be stopped. Pain relief is not an issue for her, but relief of her suffering is, and she sees this relief as coming via her death. She is asking for euthanasia, where the intention of any action by a physician or other would be to take her life. Is this a morally permissible act by the physician, or, indeed, by anyone? Viewpoints vary, but the weight of thought would say no.

What then, are appropriate professional obligations to her? The first is to explore her request fully, to come to know its origins—her thoughts, feelings, hopes and despairs—in order to seek avenues for intervention.26,27,28,29 She should be reassured that while euthanasia is not possible, nothing will be done to prolong her life. She should be involved in open conversations about her options to decline resuscitation, artificial feeding, hydration, and antibiotics. A trial of antidepressants may lift her mood. Her spells of choking and secretions should be vigorously controlled with appropriate therapeutics. Ultimately, this may require sedation. She should receive ongoing support of a tender, personal, and caring type. This may require the use of an interdisciplinary team and special volunteers. Every effort should be made to treat her as the unique person that she is and to involve her in life as much as she wishes to participate. She should be provided opportunities to tell her story, and to express her thoughts about her life, illness, present, and future.

Conclusions

Ethical decision-making in the care of dying patients is a dynamic process requiring reflection, discussion, and evaluation. Physicians and members of the health care team must be knowledgeable about the fundamental principles of ethical thought that may guide analysis of complex decisions. They must engage in a process of decision-making that first involves the patient as the one for whom they care, but also extends to include the people who share the patient's life.

Open dialogue with patients, families and other health professionals encourages the expression of diverse perspectives on these very complex issues. In the end, it can be difficult to find the "right" answer. However, it is important for health professionals, as moral beings, to have struggled with the issues and, after careful consideration, to have arrived at the best decision possible.

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