Ethical Issues in End-of-Life Care

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The issues associated with appropriate end-of-life interventions involve ethical, moral, and legal decisions by patients and their physicians.

Background: Physicians who treat patients approaching the end of life often face moral, ethical, and legal issues involving shared decision making, futility, the right to refuse medical treatment, euthanasia, and physician-assisted suicide.

Methods: The author examines cases that involve these issues and also reviews the ethical principles that guide current medical practice. Issues such as end-of-life ethical questions, the right to life-sustaining therapy, medical futility, the distinction between killing and allowing to die, and physician-assisted suicide are discussed.

Results: The principal problem involves the appropriate use of technology at the end of life. While developments in technology have enhanced our ability to prolong life, issues have also arisen regarding the resulting quality of life, the sometimes marginal benefits to our patients, and the burdens that this technology imposes on patients, families, and society.

Conclusions: Legal and ethical issues continue to confront patients, courts, and physicians. A better understanding of these issues and an awareness of the availability of effective palliative care will help physicians, patients, and families adequately address the end-of-life issues that are an intrinsic part of medical care.

Introduction

Medical's technical advances of the past few decades have cast a shadow over its long-held ethic of compassionate care. The main problem has been the appropriate use of technology at the end of life. Should it be used on everyone, regardless of the chance of successful outcome or the burdens it imposes? If not, what ethical parameters guide the use and non-use of medical interventions? These questions are most sharp at the end of life because the burdens of intervention are often high, the benefits are marginal, and quality of life is markedly diminished. This article reviews the ethical principles that guide medical practice and then focuses on end-of-life ethical issues such as the right to life-sustaining therapy, medical futility, the distinction between killing and allowing to die, and physician-assisted suicide.

Ethical Principles

The core principles of medical ethics date from antiquity and are commonly labeled "beneficence" and "nonmaleficence." The principle of beneficence holds that physicians should aim to "benefit the sick," while nonmaleficence means to "do no harm" in the process. These principles are reflected in medicine's chief goal, which is to help the sick by returning them to health and lessening the suffering and decline that is often associated with their diseases. The central question in the care of the dying is the appropriate use of life-sustaining interventions. In some cases, there is little or no benefit to be gained by these interventions, and yet the potential for significant harm commonly remains. Ordinarily, when the benefits are clearly outweighed by the potential harms of intervention, the use of that intervention is properly regarded as inappropriate. But who has the ultimate authority to decide the matter of appropriateness? Should it be the physician alone? Should inappropriateness be decided at the policy level?

From an ethics point of view, the patient is the one to decide about forgoing life-sustaining interventions, based on the third ethical principle — patient autonomy. The principle of autonomy, or respect for persons, has its roots in analytic philosophy and has become synonymous with the concept of self-determination. This concept was expressed well by Justice Cardozo in a famous medical malpractice case: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." The principle of autonomy lies at the root of the medical and legal doctrine of informed consent and also at the root of decisions by patients to forgo life-sustaining treatment at the end of life.

The fourth ethical principle is that of distributive justice, which guides the fair allocation of medical resources. Justice considerations arise in end-of-life care when one compares the high cost of marginally beneficial end-of-life care to the lack of funding for the basic care of a large portion of our country's residents. While the issues surrounding medical costs and the design of just health care systems are complex and important, they require a social policy level approach and should not be left simply to the physician at the bedside. The principle of justice is mentioned to set it apart from end-of-life ethics decisions at the bedside. In the current climate of increasing desire for a dignified death, if a better job were done of honoring patients' wishes to forgo expensive life-prolonging intervention, then both justice and autonomy would be served.

Shared Decision Making

In most cases, ethical treatment decisions should be shared between physician and patient. The physician has an obligation to inform the patient of established treatment options and then to recommend the treatment he or she believes is in the patient's best medical interest. The patient then accepts the physician's recommendation and consents to treatment, chooses an option other than the recommended one, or chooses to forgo the treatments altogether. In each case, the physician fulfills the ethical obligation to benefit the patient while minimizing harm. The patient, in turn, exercises his or her autonomy in either choosing treatment or refusing it. Even though this shared decisional process may result in conflict, in most cases of treatment refusal the patient's autonomy should prevail. This does not mean that the physician should not attempt to persuade the patient to act in what the physician believes to be the patient's best medical interest, but it does mean that the physician should not attempt to coerce the patient's decision.

The Right to Refuse Medical Treatment

The right to refuse medical treatment is well established in medicine and in law. The legal tradition of the right to be left alone has deep roots. When cases arose asserting that a patient has a right to be free of unwanted medical intervention, the right was readily recognized and clearly affirmed. These legal cases can be categorized into four classifications: (1) the patient with decision-making capacity, (2) the patient without capacity but who had earlier expressed treatment preferences for end-of-life care either verbally or in a written advance directive, (3) the patient without capacity who had made no prior expression of treatment preferences, and (4) the patient who never had the capacity to make treatment decisions. In cases of patients with intact decision-making capacity, courts have ruled that such patients have the right to refuse medical interventions even when those interventions are life-sustaining. In Satz v Perlmutter, a competent ventilator-dependent patient with amyotrophic lateral sclerosis wanted his...
in cases where patients have lost their capacity but had indicated in an advance directive that they did not want life-prolonging procedures, courts have ruled that their advance wishes should be followed. In situations where there is no written advance directive and the patient lacks decision-making capacity, courts have articulated standards for proximate decision making. This means that an individual other than the patient assists in decision making for the patient. The courts have reason to believe that the loss of capacity to exercise the right to refuse treatment does not entail the loss of the right itself. They have further reasoned that in order to prevent the right from being extinguished in a practical sense, another person must exercise the right on the patient's behalf.

In cases where patients have expressed their wishes prior to losing capacity, the proxy decision makers should follow those wishes rather than make their own judgment about what to do. This is referred to as "substituted judgment" because the proxies substitute the patients' prior judgment about treatment matters for their own. This is not only an important legal concept, but also one that has practical application in counseling proxy decision makers at the bedside. Many proxies feel uncomfortable in deciding to forgo life-prolonging interventions because they see themselves as deciding between life or death for another person. The actual role of the proxy, however, is not to make the decision but to help carry out the patients' wishes. This is relatively easy when the patient has taken the time to complete an advance directive. In such cases, the proxy's role is often to clarify the interpretation of vague statements in the directive and to help craft the details of the patient's palliative care plan. Matters can become more difficult when the proxy must recall past oral statements by the patient about how he or she would want to be cared for in an end-of-life or terminal situation.

In cases where the patient has never communicated thoughts about end-of-life care or has never had the capacity for such thoughts, the proxy cannot make a substituted judgment since no prior judgment by the patient exists. Despite this, one early court case strained to apply the substituted judgment standard in deciding whether to authorize chemotherapy to treat leukemia in a 67-year-old competent man with an approximate mental age of 2. Most courts, seeing the illogic of basing decisions on the imagined choices of the never-competent, have rejected this approach as misguided. They have instead adopted the "best interest" standard of proxy decision making. This standard simply requires the proxy to make the decision that is in the patient's best medical interest. It is not the proxy's decision alone; it is a process of shared decision making with the attending physician.

A patient's right to refuse treatment, whether exercised directly or by proxy, is not an absolute right. Many state courts have identified four social interests that must be balanced against a person's right to be free of unwanted medical intervention. These are the preservation of life, the prevention of suicide, the protection of third parties, and the preservation of the ethical integrity of the medical profession. In most treatment refusal cases, these state interests are not found to outweigh a competent adult's right to refuse unwanted medical intervention. However, in some cases, the right to refuse treatment is overridden. An example of this is a court-ordered blood transfusion to save the life of a single-parent Jehovah's Witness who would leave minor children as wards of the state if life-saving transfusion is withheld. In cases such as this, many courts have held that the state's interest in protecting the children outweighs the parent's right to refuse unwanted transfusion, even though the reason for refusing is based on a deeply held religious belief.

Forgoing Treatment on the Basis of Medical Futility

It is well established that there is no ethical obligation for physicians to provide treatment that is futile. The question, however, is what constitutes futile treatment. Unfortunately, medical futility can have several meanings. Failure to clarify the term can lead to miscommunication and masking of differing value judgments and biases, thus enabling a subtle form of paternalism. For example, in explaining to a patient that cardiopulmonary resuscitation (CPR) would be futile, it is not uncommon for the physician to mean that CPR would have a very low chance of success, while the patient interprets the meaning of term to be that treatment has no possibility of success. If the patient then agrees to forgo CPR, the decision will have been based on a misunderstanding. For this reason, it is important to be explicit about these matters by using plain language instead of hiding value judgments under the cloak of medical futility.

Medical futility concepts can be organized as follows: The first division of futility is divided into the categories of post-hoc futility and predictive futility. In post-hoc futility, treatment has been tried and has failed. We see in retrospect that a treatment that perhaps held out some hope has proven to be futile. Post-hoc futility is useless for those who want to use futility as a reason not to try a treatment in the first place. Predictive futility, on the other hand, involves predicting that a treatment will be futile and therefore should not be tried.

Predictive futility can be divided into several types: conceptual futility, probabilistic futility, physiologic futility, and doctor-patient goal disagreements. Conceptual futility is simply the refusal to perform a treatment, based on a particular concept or definition, the example being brain death. The medicolegal concept of death holds that ventilator-dependent patients who have suffered "irreversible cessation of all functions of the enbrain including the brain stem" are dead. In such cases, the ventilator is by definition a futile intervention because it cannot bring the patient back to life. While "brain death" has become a medicolegal standard in the United States, some have voiced religious objections to the standard. Because of this, at least two states have passed laws allowing a "religious exemption" to the brain-death standard. Apart from religious reasons, cases have occurred where family members simply do not accept that their "brain-dead" loved one is in fact dead. In these cases, the law would allow physicians to discontinue the ventilator without family permission. In practice, however, despite the fact that continued ventilator use is conceptually futile, time is usually given to the family to come to terms with the patient's death before the ventilator is removed.

Probabilistic futility means that a treatment with a very low chance of success can properly be regarded as futile. For example, some would call a 1% chance of surviving CPR as futile CPR. This kind of futility is never absolute, and it entails making value judgments about what risks are worth taking. Because of this, physicians should not make unilateral futility judgments because their values may not reflect those of the patient. Instead, the information should be communicated to the patient, and a process of shared decision making should be followed.

Physiologic futility comes in two forms. The first is called medical nonsense; the second is medical impasse. An example of medical nonsense is a patient for whom antibiotics to treat a viral upper respiratory infection are prescribed. In this case, the physician can unilaterally refuse to give antibiotics on the ground that the antibiotics are a futile intervention. There is no possibility of benefit, while potential for harm remains. Medical impasse occurs when a person dependent patients who have suffered "irreversible cessation of all functions of the entire brain including the brain stem" are dead. In such cases, the ventilator is by definition a futile intervention because it cannot bring the patient back to life. While "brain death" has become a medicolegal standard in the United States, some have voiced religious objections to the standard. Because of this, at least two states have passed laws allowing a "religious exemption" to the brain-death standard. Apart from religious reasons, cases have occurred where family members simply do not accept that their "brain-dead" loved one is in fact dead. In these cases, the law would allow physicians to discontinue the ventilator without family permission. In practice, however, despite the fact that continued ventilator use is conceptually futile, time is usually given to the family to come to terms with the patient's death before the ventilator is removed.

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The last futility concept is doctor-patient goal disagreement. In the case of Helga Wanglie, a ventilator-dependent patient in a permanent vegetative state, the physician regarded the ventilator as futile because it could not improve and thus benefit the patient. The patient's husband, however, did not see the ventilator as futile because it was keeping his wife alive. In this case, we have a disagreement between two different goals. The ventilator could not meet the physician's goal of health improvement, but it could meet the husband's goal of life prolongation. In such cases where value preferences exist about what goals are worth pursuing, the decision should be a shared one between the-doctor and the patient (or the patient's proxy). The physician would not be justified in making a unilateral decision to discontinue the ventilator. On the other hand, the physician who believes that continued ventilation would be morally objectionable is free to preserve his or her moral integrity by withdrawing from the case.

Killing vs Allowing to Die

When life-sustaining treatment is discontinued, whether on the ground of medical futility or patient autonomy, there can be uneasiness about our actions. This often stems from failing to distinguish clearly between causing the patient's death or merely allowing the patient to die. In the typical scenario of a permanently unconscious ventilator patient, the patient is alive until the physician removes the ventilator, whereupon the patient soon dies. The proximity of the patient's death to the physician's removal of the ventilator leads some physicians to wonder whether they have indeed caused the patient's death. By contrast, in the case where the ventilator is never utilized, death is neither caused nor precipitated by the physician but is instead the result of the patient's disease process. Because of this, many physicians are more comfortable with not starting treatment than with stopping it.

The counter to this concern is to regard the ventilator as an optional form of external support. While the ventilator does sustain life, it is clear that a person who wishes to forgo has the right to do so. An unambiguous example is that of an irreversibly incapacitated, terminally ill patient who had earlier prepared an advance directive stipulating that the ventilator be discontinued and was allowed by the court to direct physicians to remove the ventilator.
mechanical ventilation should not be used if his or her capacity was irreversibly lost and if the disease was terminal. WJ, eds. Ethics in Medicine: Historical Perspectives and Contemporary Concerns. Cambridge, Mass: MIT Press; 1977:6 -7.

The Quill opinion argued that a person has a right to hasten death but that laws prohibiting physician assistance in suicide should not be used if his or her capacity was irreversibly lost and if the disease was terminal. If these criteria are met before the need for ventilation arises, then the ventilator should not be started. On the other hand, if the ventilator was started before the patient became terminal and irreversibly incapacitated, the ventilator should be discontinued once these conditions have been clearly met. In discontinuing the use of the ventilator, the physician is not causing death but is appropriately removing a form of terminal medical support the patient refused in advance. The natural forces of the patient’s illness continue unopposed once the ventilator is removed, and quite predictably, the patient dies. The patient’s death is caused by the disease rather than by the physician.

Euthanasia and Physician-Assisted Suicide

In the case of euthanasia, the physician takes the patient’s life. While the term euthanasia has been variously defined, in this article euthanasia refers to an act in which a physician directly and intentionally causes a patient’s death by medical means. For example, a physician commits euthanasia when he or she deliberately injects a lethal amount of potassium chloride into a patient for the express purpose of terminating that patient’s life. Thus described, euthanasia is commonly distinguished from murder because its motive is merciful rather than malicious; however, it is nevertheless a form of homicide and remains illegal in the United States. When the physician performs euthanasia with the consent of the patient, it is called voluntary euthanasia. When euthanasia is performed without patient choice, such as may be the case with incapacitated patients, it is called nonvoluntary or nonchoice euthanasia. Involuntary euthanasia involves performing euthanasia against the patient’s wishes.

Physician-assisted suicide is a form of voluntary euthanasia that is legal in the state of Oregon. In Oregon, a physician can prescribe a lethal amount of medication for a patient so that the patient can commit suicide with the medication if he or she so chooses. It is a form of voluntary euthanasia because the physician agrees to participate in a plan to cause the patient’s death and supplies the lethal medication that is used to cause death. In voluntary euthanasia, as defined above, the physician acts alone to terminate the patient’s life, whereas in physician-assisted suicide, the physician and the patient act together to cause the patient’s death.

The Hippocratic Oath, to which American medicine has traditionally appealed for its moral bearings, expressly prohibits physician-assisted suicide and euthanasia. The oath reads, “Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course.” It is telling to note that during the time of Hippocrates, when medicine’s power to effectively treat disease and ameliorate suffering was far less than it is today, assisted suicide and euthanasia were regarded as radically incompatible with physicianhood. This at least suggests that those is favor of physician-assisted suicide and euthanasia have very different ideas about physicianhood and the moral limits of medicine. It is also telling that the public interest in physician-assisted suicide comes at a time when the palliative powers of American medicine are greater than they have ever been before. This suggests that perhaps the public is significantly unaware of the advances and availability of palliative medicine or that palliative care it is woefully understudied. While there is no doubt the case for some portion of the public, others in our society wish to have physician-assisted suicide and euthanasia as options along with the benefits of palliative care. The chief argument for this is based on autonomy, but it is an argument that begs the question of whether it is proper for a physician to play an active role in causing a person’s death via lethal doses of medication.

In euthanasia and physician-assisted suicide, the core ethical issue for medicine is the rightfulness or wrongfulness of a physician intending and acting to cause the death of a patient. Unfortunately, this issue is easily obfuscated. An example of this occurred in Quill v Vacco, one of two recent federal appellate court cases that argued for a right to hasten death. The Quill opinion argued that a person has a right to hasten death but that laws prohibiting physician-assisted suicide prevent the equal exercise of this right. This can be illustrated with an example involving two similarly situated patients. Patient A has terminal lung disease and is on a ventilator, while patient B is terminal with AIDS and is not on a ventilator. According to the Quill court’s logic, patient A is able to hasten their death by directing that the ventilator be discontinued, while patient B cannot hasten their death because the law regards physician-assisted suicide as a crime. The court concludes that laws prohibiting physician-assisted suicide were unconstitutional because the laws set up an inequality in the law.

The reality is that there never has been a right to hasten one’s death, but a right to refuse unwanted medical intervention has been recognized. Patient A exercises the right to refuse unwanted intervention by directing doctors to discontinue the ventilator. Similarly, patient B exercises the right to refuse unwanted intervention by deciding not to go on a ventilator in the first place. The Quill court’s view that patient A is hastening death by discontinuing the ventilator shows that they do not understand the difference between killing and allowing to die. Furthermore, in suggesting that discontinuing the ventilator hastens death, the court implies that the palliative powers of American medicine are greater than they have ever been before. This suggests that perhaps the public is significantly unaware of the advances and availability of palliative medicine or that palliative care it is woefully understudied. While there is no doubt the case for some portion of the public, others in our society wish to have physician-assisted suicide and euthanasia as options along with the benefits of palliative care. The chief argument for this is based on autonomy, but it is an argument that begs the question of whether it is proper for a physician to play an active role in causing a person’s death via lethal doses of medication.

The Legal Slippery Slope

The US Supreme Court rejected the arguments of the two federal appellate courts that laws prohibiting physician-assisted suicide were unconstitutional. However, the Supreme Court did not say that states were obligated to prohibit the practice. This leaves the door open for states to follow Oregon in legalizing physician-assisted suicide. The Oregon law was careful not to characterize physician-assisted suicide as a right, but if it is ever deemed to be one in future court decisions, this designation will almost certainly entail the extension of this right to incompetent patients, just as has been the case with the right to refuse treatment. With the latter, court after court has argued that losing the capacity to exercise a right does not mean that the right no longer exists. Furthermore, to prevent the right from being extinguished in a practical sense, some other person must exercise the rights of the incapacitated patient for that patient. Thus the process of proxy decision making came into being. This same process could take place with physician-assisted suicide, especially when the courts begin to see cases involving incapacitated patients who had earlier stipulated that they would want physician-assisted death in the event of terminal illness and irreversible loss of capacity.

If physician-assisted suicide is regarded as a right, it will very likely be extended to incapacitated patients in order to avoid the practical extinguishing of their rights. However, since the patient will not be able to exercise it, proxy decision making would be utilized. Also, since the incapacitated patient cannot participate in physician-assisted suicide, it will become the physician’s act alone. Thus we will have moved to euthanasia. Still further, if this right is extended to the case of the incapacitated terminal patient who left no past wishes, as it has been in the case with the right to refuse treatment, then we will have legalized nonvoluntary euthanasia. Proxies and physicians will then be making euthanasia decisions because it is deemed in the patient’s “best interest” to be dead. The fact that such potential exists in our legal system, which judges cases and advances law by ruling on precedent, should give us pause. Alternatively, the current effectiveness of palliative care in addressing the full spectrum of end-of-life issues leaves us with no good reason to throw open the door of euthanasia that Oregon has left ajar. Efforts should instead be put toward optimizing the use of palliative care and making it available to all who need it.

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