Limitation of Treatment at the End-of-Life: Withholding and Withdrawal

Arthur R. Derse, MD, JD

Center for the Study of Bioethics, Medical College of Wisconsin, 8701 Watertown Plank Road, Milwaukee, WI 53226-0509, USA

The recognition of the ethical and legal appropriateness of withholding or withdrawing life-sustaining medical treatment is now ingrained as an essential part of the medical decision making process in end-of-life and palliative care. Just a generation ago, however, it was less clear. At that time, as a result of new technologies, such as cardiopulmonary resuscitation, ventilation, and nutrition and hydration, physicians were able to prolong patients’ lives beyond previous limits. The paradigm case was that of a patient who was permanently unconscious and dependent on continued artificial ventilation. Medical professionals faced a new set of ethical and legal questions: Under what circumstances, if any, may one stop life-sustaining medical treatment? Must medical measures that were initiated to sustain life be continued until the patient’s death? What role should the patient’s wishes play? Is withholding or withdrawing life-sustaining medical treatment a form of homicide or suicide? Ethicists, legal professionals, and medical practitioners are still struggling for answers and a consensus to many of these questions.

The crux of the problem was this: If the expected result of intentionally withdrawing a life-sustaining medical treatment (such as a ventilator) was death, was not this act of withdrawal an intentional cause of the patient’s death just as surely as if the physician had ended the patient’s life by lethal injection? Philosophers and theologians analyzed this question in different ways. The theological approaches included those of the Roman Catholic tradition that differentiate ordinary care, which is obligatory, from extraordinary care, which may be discontinued. Factors to be considered in determining if a treatment is extraordinary include the gravity of the burdens of that treatment to the patient or...
others. If the treatment was a grave burden, it could be discontinued [1]. In considering limitation of treatment, many philosophers distinguish between the duty not to kill (a negative duty) and the duty to save life or not allow the patient to die (a positive duty). They see a sharp distinction between killing and allowing to die, as does the tradition of United States law and many religions. The withdrawal of life-sustaining medical treatment, in this view, allows the disease process to take its course toward death, a course that artificial life-sustaining measures merely postpone. The withdrawal is justified as a removal of medical treatment, not an act of killing [2]. An additional justification to be considered in the decision to withhold or withdraw life-sustaining medical treatment is patient consent, or evidence that the now nondecisional patient, would have consented. These philosophical foundations provided the justification for limitation of treatment. Some have argued that there is no inherent moral difference between killing and letting die [3] and that, for instance, stopping a ventilator, even with a patient’s consent, is a form of permitted killing [4]. This latter view, however, has not been widely adopted, and courts and legislatures readily continue to differentiate the two. Thus, most medical ethicists, legal analysts, and clinicians recognize a difference between withdrawing life-sustaining medical treatment (which may result in death) and intentionally causing a death. The term “passive euthanasia” (euthanasia, from Greek, meaning “good death”) was sometimes used to describe the act of withholding or withdrawing life-sustaining medical treatment that resulted in death to distinguish it from the act of “active euthanasia,” a deliberate causing of death by an action such as a lethal injection. The term “passive euthanasia” has fallen into disuse in the clinical realm because of the confusion engendered by the common understanding of the term “euthanasia” as equivalent to “active euthanasia.”

The role of the law and legal precedent in limitation of treatment

Legal cases often serve as societal benchmarks of bioethical thought, debate, and, at times, consensus. Cases tried and then appealed, decided, and reported by appellate and supreme courts act as foci for discussion in the medical ethical literature and the news media, and act as mandatory precedent for future cases in their own jurisdictions and persuasive precedent for other jurisdictions. Statutes passed by federal and state legislatures act as social parameters of conduct in medical ethics cases and constrain the actions of physicians, patients, and families while delimiting the area of legal safe harbor. The law often serves as a minimal ethical standard of conduct (ie, doctors should neither harm patients nor intentionally cause a patient’s death). Although these legal rules set minimal standards, the law cannot mandate with any effectiveness the important attributes of ethical decision making by physicians in end-of-life care, such as care, compassion, and the necessity of engendering trust. At times, the law may conflict with other laws or with medical ethical standards. An example is the current laws in the neighboring states of Oregon and California with opposite views on physician-
assisted suicide. The language of the law is often an inapt instrument with which to shape the interaction among doctor, patient, and families [5]. Nonetheless, the language of the law is a part of the lingua franca that is the common language of bioethics and that seeps into the general societal consciousness of end-of-life care, such as “do not resuscitate,” “withdrawal of life-sustaining medical treatment,” and “brain death.” The common language of the law and legal cases has marked the progress of a societal agreement and, to a significant degree, consensus on the issues of limitation of medical treatment [6].

After an initial period of uncertainty in judicial opinion, a consensus emerged in the law that withholding or withdrawing life-sustaining medical treatment is considered neither homicide nor suicide, but a permitted removal of medical artifice [7]. Courts made an important distinction between intentionally causing a patient’s death and allowing a patient to die as a result of the withdrawal or withholding of life-sustaining treatment [8–10]. The former remains a crime, and the latter is now a recognized part of ethical medical practice [11].

Is withdrawing ethically and legally equivalent to withholding?

This seminal question has been debated in philosophy and law. Intuitively, these may not seem equivalent. In the case of withholding, an offer of treatment has been made, whereas withdrawal entails an offer that has been accepted and subsequently retracted [12]. However, despite this intuition of moral difference, many ethicists have analyzed these actions to be morally equivalent, in part on the basis of the illogical consequences of considering them differently.

If withholding is thought to be less morally troubling than withdrawal, then, once begun, a treatment becomes morally troublesome to stop. An “upfront barrier” to treatment is thus created. A treatment would not be tried to see whether it is effective because if it were not, or if the patient found the treatment too burdensome, the moral difficulty of withdrawing the treatment would preclude stopping the treatment. Thus, clinicians, patients, and families would be reluctant to begin any treatment for fear of dooming the patient to being tethered to the medical treatment in an unending limbo of dependence.

The equivalency of withholding and withdrawal also might not at first be intuitively apparent from a legal viewpoint. Physicians do not have an obligation (absent an emergency) to begin treatment of a patient unless there is a prior doctor-patient relationship. However, once treatment is begun, stopping that treatment might be deemed abandonment under some circumstances. Nonetheless, this intuitive difference does not withstand legal scrutiny. The difference lies in the fact that even if there is a prior doctor-patient relationship, treatment need not be continued if the treatment is either unwanted by the patient or would be ineffective toward the treatment goal. Thus, the legal analysis of withholding and withdrawal has made them equivalent to unwanted (and therefore not required) medical treatment. Numerous legal cases have found withholding and withdrawal legally equivalent.
The consensus on limitation of treatment

In parallel developments in the evolution of legal and ethical analysis of treatment withdrawal in the United States, a crucial factor has been the evolution of the concept of autonomy (ie, self-governance) and personal freedom [2]. As the law of informed consent developed, it first established that the patient of sound mind and adult years should be the sole arbiter of what shall be done to his or her body [13]. The fact that the treatment is beneficial does not justify treatment without permission. Patients have the right to be informed of the risks and benefits of the treatment, as well as the results of alternative therapies and the consequences of no treatment [14]. In most jurisdictions, the risks disclosed are those that a reasonable patient would find material in the decision-making process. It is also recognized that patients may refuse treatment as long as they understand the consequences of the refusal [15]. Because the patient’s consent is essential for continued treatment, the patient or surrogate who refuses continued treatment withdraws the fundamental legal and ethical basis for treatment. This autonomy in decision making by patients about medical care would serve as the basis for the developing legal right to refuse life-sustaining medical treatment. Legal analysis derived authority to withhold and withdraw treatment from patients’ right to be free of unwanted medical treatment. Other countries and cultures may not place as much emphasis on patient autonomy in considering limitation of life-sustaining medical treatment, instead placing these decisions solely in the hands of the physician.

Over the past 3 decades, a consensus has developed in ethics and law about certain principles of withdrawing and withholding of life-sustaining medical treatment. Though the consensus of these principles does not reach the level of unanimity, the consensus has been accepted broadly in ethics and law. The underlying principle of the consensus is that patients who have decision-making capacity may refuse unwanted medical treatment, even if this may result in their death [16]. This consensus was achieved after clinicians, ethicists, courts, and legislatures struggled over the question as to whether a patient with a terminal illness may refuse treatment, and once that question was answered in the affirmative, whether a patient without a terminal illness could refuse life-sustaining treatment [8–10]. The imperative of personal autonomy was supported by the legal principle of the common-law respect for bodily integrity and the liberty interest articulated in the 14th Amendment to the Constitution. The most important legal expression of this principle was enunciated by the United States Supreme Court in the Cruzan case, where the question was whether and under what circumstances an individual has the right to refuse treatment [21]. This case involved a patient in a persistent vegetative state (PVS) who was dependent on artificial fluid and nutrition. The court answered in the affirmative that patients do have such a right to refuse and this right could be asserted on their behalf despite their incapacity, although it allowed states to set the bar at a high level for evidence of the patient’s wishes [18]. Other state courts extended this principle to cases where the patient does not have a life-threatening illness or PVS. The
patient with decision-making capacity may legally refuse any life-sustaining medical treatment. As a result, there are few situations in limitation of treatment that cannot be resolved legally and ethically by the physician in collaboration with the patient and family. Only rarely does limitation of life-prolonging treatment at the end of life require court intervention.

Types of treatments that may be limited

Initial questions concerning the types of medical treatment that may be limited focused on resuscitation and ventilation. The ability to attempt cardiopulmonary resuscitation (CPR) of patients who had previously met the criteria for cardiopulmonary death was an unparalleled technological achievement. However, CPR was initially developed for use in reversible cardiac disease, and the universal application of CPR to all patients in cardiac arrest resulted in ethical quandaries. Analysis of patient outcomes shows that only a minority of patients would survive the attempt at resuscitation, and only a minority of those initial survivors would improve sufficiently to be discharged from the hospital. The majority would die in hospital, often after prolonged periods of unresponsiveness. Do-not-resuscitate (DNR) orders were developed to distinguish those for whom resuscitation should not be attempted, either on the basis of patient desires or expected medical ineffectiveness [19]. Courts have also upheld the validity of DNR orders, and DNR orders have achieved widespread acceptance [20]. As a result, most expected deaths in the hospital are accompanied by DNR orders.

The use of ventilators, another important technological stride, gave rise to the phenomenon of patients who could not be weaned from them. These patients ranged in neurological state from fully conscious to absent brain activity. One of the first ethical dilemmas of this technology was whether to continue ventilation for patients whose brain and brain stem were not functioning, but whose heart continued to beat. A recognition of the irreversibility of this state and the impetus for organ procurement for transplantation led to the recognition of brain death and the codification of statutes defining it [21]. Thus, the ethical and legal impediments to withdrawal in cases of brain death were cleared, but this ethical and legal consensus has not been unanimous. Some religious communities do not recognize brain death, and in two jurisdictions legal exceptions have been carved into the brain death regulations, allowing members of those religious communities to be declared dead only by cardiopulmonary criteria [22,23]. The recognition of ventilation as a technological treatment that may be withdrawn was an early consensus in ethical and legal analysis. Courts have allowed ventilators to be removed from patients in persistent vegetative states [17] and from patients who did not lose decision-making capacity and were permanently dependent on the ventilator [8].

Perhaps the most problematic issues surrounding treatment limitation have centered on the technology of parenteral fluid and nutrition. Artificial fluid and nutrition have been considered by some as merely medical administration
of ordinary care in the form of food and water, and thus required treatment. Certainly, the symbolic value of feeding in human society is an important symbol of providing for the most basic needs of those unable to feed themselves. However, tube feedings are not merely extensions of ordinary feedings. Tube feedings are a bodily intrusion and often require restraints [24]. For patients facing terminal illness, loss of appetite is part of the dying process, and studies indicate that tube feedings have not been shown to prevent aspiration pneumonia or decrease mortality in patients with dementia or stroke [25,26]. Additionally, because of ketonemia, patients at the end of life do not suffer hunger, and symptoms of thirst or dry mouth can be ameliorated though the use of ice chips or swabs [27,28]. Tube feedings have been legally recognized as medical treatments, with burdens as well as benefits and, as such, may be withdrawn [18].

Other treatments that can be considered life-sustaining medical treatment and may be withdrawn include the use of vasopressors, transfusions, antibiotics, and renal dialysis. In sum, there are no limitations on the type of treatment that may be withheld or withdrawn under appropriate circumstances. Withholding of CPR, withdrawal of ventilation, and withholding or withdrawal of parenteral nutrition and hydration are all ethically and legally permissible, as is withholding or withdrawing any other form of medical treatment [29]. Once a decision has been made to withhold or withdraw life-sustaining medical treatment, appropriate palliative care measures should be instituted [30].

**Deciding for patients who lose decision-making capacity**

Once it was established in ethics and law that competent patients had the autonomous right to refuse life-sustaining medical treatment, the next ethical consideration became determining when the patient had the competence to make the autonomous choice to refuse. Few patients with life-threatening illnesses retain the ability to make decisions about their health care up until the moment of death. Instead, most patients are incapacitated for some period at the end of life. Despite this incapacity, limitation of treatment may be appropriately accomplished, ethically and legally, through the patient’s right to refuse life-sustaining medical treatment, which may be asserted even if the patient is incompetent. The crucial first step in the process of asserting this right for the patient is determining when the patient is no longer decisional.

Decision-making capacity is the ability of the patient to make medical decisions. This is different from legal competence. A declaration of incompetency by a court is a formal process that strips the individual of the right to make decisions about their person or their property, or both, and entails the appointment of a guardian to make those decisions.

Decision-making capacity is a medical determination of the individual’s ability to make medical decisions and is related to the decision to be made. Determination of the capacity of a patient to decide on a course of treatment must
relate to the patient’s abilities and the requirements of the medical decision and its likely consequences—the greater the consequences, the greater the need to ensure that the patient possesses the necessary capacity to make the decision. Generally, patients are deemed medically decisional until proven otherwise [31]. There are three elements to be evaluated: (1) The patient must possess the ability to comprehend the information about the medical problem and appreciate the impact of the disease and the consequences of various options for treatment, including forgoing treatment; (2) the patient must possess the ability to evaluate the options by comparing risks and benefits of each option, to deliberate in accordance with the patient’s own values, and to make choices that are not irrational. The patient should also be able to maintain a consistent choice over time; and (3) the patient should be able to communicate his or her choice [32].

A lack of decision-making capacity may be caused by any break in the three elements of the chain of decision making, including the ability to (1) understand; (2) reason and evaluate; or (3) communicate a decision. Some patients, because of age or medical condition, patently lack decision-making capacity (eg, comatose patients, infants, and young children), and some patients with significant medical problems at the end of life, such as those causing major metabolic abnormalities or problems in mentation, such as minor degrees of disorientation or early dementia, may still retain decision-making capacity [33]. Similarly, courts have recognized that patients who may not be oriented may still be decisional in that they can evaluate medical treatments according to their personal values and decide to refuse life-sustaining medical treatment [34]. Physicians who are taking care of patients for whom a discussion of limitation of treatment may be appropriate should assess the patient’s decision-making capacity to determine whether the patient can participate in medical decision making [35].

As stated, patients who lack decision-making capacity have the same ethical and legal rights as patients who are decisional to have unwanted medical treatment withdrawn or withheld. However, because the basis for treatment limitation rests on the right of patients to evaluate burdens and benefits of treatment and to express their decision to refuse life-sustaining medical treatment, when patients can no longer decide and express themselves, mechanisms have been developed to address these decisions in advance of the patient’s incapacity.

When patients lose decision-making capacity, in some cases there is also a legal determination of incompetence, and a guardian is appointed. This is often a slow and costly process. The guardian’s charge is to make decisions that are in the best interest of the patient, known as the best interest standard, and this may conflict with making decisions according to the patient’s wishes for medical decision making, known as the substituted judgment standard. Because of the procedural problems and restrictions in health care decision making by guardians and the recognition of the importance of recording the patient’s wishes to apply an accurate substituted judgment, legal documents known as advance directives were created, so called because they give directions to physicians in advance of patient incapacity about the patient’s desires concerning future health care choices.
One type of advance directive, the living will, was developed to provide direction that life-sustaining medical treatment should be forgone if the patient is no longer decisional and has a terminal condition or PVS [36]. One limitation of this living will is that it is used only for patients who are in PVS or have a terminal condition, yet many patients who become incapacitated face not only these specific conditions but a varied range of medical situations and consequent treatment options. Partly to deal with this limitation of the living will, the power of attorney for health care was developed. If the patient becomes incapacitated, the power of attorney for health care gives medical decision-making authority to an appointed person, known as an agent or proxy [37]. The agent is charged with acting in accordance with the patient’s known wishes concerning medical care, or in accordance with what the patient would have wanted—the substituted judgment standard. The power of attorney for health care was noted in the Cruzan case as an advance care planning device that would have easily resolved the issue of evidence of the patient’s wishes [21]. Spurred on by this, Congress enacted the Patient Self-Determination Act (PSDA) to require health care facilities to inform patients of their right to forgo life-sustaining medical treatment and to use advance directives to give direction upon incapacity [38]. Advance directives typically give immunity from prosecution to physicians who, in good faith, follow these directives. Even though advance directives tend to be written to comply with state-specific legal requirements, they can be written to take advantage of the broadest possible validity among the states. Even beyond the state of origin and state-specific immunity provisions, these documents may be used as valid indications of patient wishes. In preparing patients for documentation of desired treatment options, physicians should engage in a structured discussion and may use a form to have the patient indicate preferences about the wide variety of possible life-sustaining medical treatments and the subsequent outcomes in light of personal values [39]. Advance directives are one key piece of the general goal of planning for medical and general care needs upon decisional incapacity at the end of life, known as advance care planning, which may include social, financial, and funeral arrangements.

The initial enthusiasm for the use of advance directives has given way to a more sobering reality—that most patients, even those facing the end of life, still do not complete the directive [40], that proxy decision makers are poor predictors of patient wishes [41], and that there is no evidence that completing the directive changes care [42]. However, advance directives remain useful as part of advance care planning for many reasons. Patients prefer that their loved ones make these decisions, even if they don’t reflect their autonomous decisions, and some promise has been shown to affect end-of-life care by incorporating the completion of these documents within a larger discussion with the patient about values that are important to the patient [43]. Even more importantly, these documents satisfy many states’ requirements for the stringent level of evidence necessary to accurately reflect that the patient would wish to refuse further life-sustaining treatment.

In the absence of an advance directive or the appointment of a guardian, many states allow spouses, family members, and others to act as decision makers under
the hierarchy as prescribed by the state surrogacy laws [44]. These laws essentially legitimize the process many physicians use for medical decision making for incapacitated patients without an advance directive or guardian, namely, turning to the patient’s spouse or others, including family and close friends, for decision making. These are the same people to whom courts would eventually turn in deciding who would best act as the patient’s guardian.

**Standard of evidence for surrogate decision making**

With the use of proxies and surrogates, one would think that once a decision maker is chosen, decision making in end-of-life care would be straightforward as long as the decision maker acts according to the patient’s wishes, if known. However, one major legal barrier to limitation of treatment remains. In many states, a proxy or surrogate may not act on the preponderance of the evidence of the patient’s wishes to forgo life-sustaining medical treatment. Instead, the law in these states requires “clear” or “clear and convincing” evidence of the patient’s wishes [45]. Although this standard is easily met by a well-written advance directive, in cases where no directive exists or the directive is not clear and convincing, proxies and surrogates are left weighing past statements of the patient that might indicate clear evidence of the patient’s wishes. Many legal cases have turned, in part, on whether the patient was sufficiently clear about his or her wishes [18]. This has only heightened the importance of the use of carefully crafted advance directives to follow the patient’s wish to forgo life-sustaining medical treatment.

The issue of appropriate limitation of treatment in the form of artificial fluid and nutrition in cases of PVS and minimally conscious states has reached the national attention in several high-profile cases [46,47], including those in which the state legislature and executives have intervened [48,49]. Though these cases continue to stimulate a national conversation about end-of-life decisions, they should not cloud this important fact: decisional patients may refuse life-sustaining medical treatment. Advance care planning creates the clear evidence that would have prevented the litigation in all of these cases. Completion of an advance directive is important and appropriate for all decisional adults, regardless of health status.

**Voluntary refusal of orally ingested fluid and nutrition**

A patient with decision-making capacity has the right to refuse life-prolonging measures, including artificial fluid and nutrition. Orally ingested fluid and nutrition that serve only to prolong the dying process should not be forced on patients at the end of life. A decisional patient facing the end of life may voluntarily choose to forgo nutrition and hydration with the understanding that this will shorten the period until inevitable death. If the patient chooses this, he or
she should also specify a concomitant refusal of artificial fluid and nutrition through an advance directive so as to provide instructions when incapacity occurs and the patient is no longer able to express a preference. The patient’s choice should also be communicated to family members, who should be assured that the patient will continue to receive appropriate comfort care. Thirst may be managed with ice chips, and hunger abates after several days. The patient who continues to refuse orally ingested fluid and nutrition will then die from dehydration or an intervening complication of the patient’s disease. This choice is one that should be chosen only by patients with decision-making capacity who understand the consequences and who have the resolve of will to continue to refuse orally ingested fluid and nutrition during the stages of dying [50,51].

**Ethical and legal issues in the use of opioids in end-of-life care**

The use of opioids in end-of-life care is necessary to relieve symptoms of pain and breathlessness, and has been the focus of ethical and legal scrutiny. The question arose whether the high doses of narcotics necessary to relieve the pain of patients in a terminal condition might cause respiratory depression as a known but unintended side effect, and ultimately, cause the death of the patient. The principle of double effect posits that if an action is taken toward a good effect, and an unintended but foreseen side effect causes harm, the actor is not morally culpable for the side effect. The unintended but foreseen side effect must be proportional to the intended good effect [52]. The principle of double effect was developed in medieval times to address the issue of the known risks of innocent deaths in a just war, but it has been used more recently in justifying the use of appropriate doses of narcotics in cases such as end-of-life care. Thus, if a physician uses a narcotic with the intention of relieving pain but not with the intention of causing the patient’s death, and the known but unintended side effect of respiratory depression causes the patient’s death, the physician is not responsible for the unintentionally caused death.

The principle of double effect has been criticized by some philosophers and ethicists because it does not make the actor culpable for causing a known possible effect. However, the focus on intent makes this principle readily understandable by legal analysis, and prosecutors, for whom the issue of intent is an essential element of proving legal culpability for causing a patient’s death. The principle has been invoked by the United States Supreme Court in its recognition of the need for adequate palliative care when considering the question of a constitutional right to physician-assisted suicide [53,54]. As a result of this legal recognition of the principle at the highest level, physicians should prescribe appropriate doses of narcotics and other drugs, such as sedatives, to relieve a patient’s pain and suffering, knowing that the principle of double effect ethically and legally justifies the small and unintended risk of respiratory depression and death.

An additional ethical and legal concern about opioid use in end-of-life care has been a perception on the part of physicians that regulatory agencies, such as the
Drug Enforcement Agency or state medical examining boards, have been zealous in prosecution of physicians for the prescription of large amounts and high doses of narcotics needed for patients in end-of-life care. Though this was true in the past, there has been a sea change in the activities of these agencies in light of the recognition of the importance of narcotic use in palliative care, and the perception on the part of physicians of the number of prosecutions far outweighs the experience of actions by medical boards [55]. The Federation of State Medical Examining Boards has adopted model guidelines for its members on the use of narcotics in patients with chronic pain [56]. At least one medical board has cited a physician for undertreatment of chronic pain [57], and another physician has been successfully sued for undertreatment of a patient’s pain [58]. Although these actions are rare, they may presage a new line of legal actions supporting the patient’s right to adequate treatment for pain. Although the use of narcotics in nonterminal patients with chronic pain continues to come under regulatory agency scrutiny, physicians treating patients at the end of life should be able to provide adequate pain relief with the confidence that medical boards know the important medical role of the appropriate use of high doses of narcotics.

Physician perception of sanctions has also exaggerated the fear of criminal prosecutions for patient deaths due to appropriate use of high-dose narcotics in end-of-life care, despite the principle of double effect. A review of recent appellate court cases and legal databases shows that this fear is unjustified. Only a handful of physicians have been successfully prosecuted nationwide for intentional homicide in the past decade [59]. These include a case of blatant euthanasia recorded and broadcast on national television and other cases with extremely troubling aspects. Physicians’ perceptions of widespread prosecution as a result of appropriate narcotic treatment is disproportionate to actual experience, and fear of criminal prosecution should not be an impediment to adequate pain relief in end-of-life care.

**Physician-assisted suicide and euthanasia**

Physician-assisted suicide is the practice by which a physician supplies a decisional patient suffering from a terminal, incurable, or painful disease with the pharmacological means to cause the patient’s death. The patient chooses the circumstances under which to take the drug, typically a high dose of a barbiturate. Euthanasia is the practice by which a physician deliberately acts to cause the immediate death of a person suffering from a terminal, incurable, or painful disease by medical administration of a lethal drug. Physician-assisted suicide is proscribed in the Hippocratic Oath and the AMA Code of Ethics [60]. The United States Supreme Court found no constitutional right to this practice [61,62], and it is illegal through statute or common law in all states but Oregon, where it was first approved by referendum in 1994 [53]. Euthanasia is forbidden by the Hippocratic Oath and by ethical codes, such as the AMA Code of Ethics [54]. It is illegal in all jurisdictions in the United States, although it is practiced legally in
the Netherlands [63]. It is important to differentiate both of these practices from the limitation of medical treatment. Withdrawal and withholding medical treatment is neither physician-assisted suicide nor euthanasia, and withholding and withdrawing medical treatment is ethically and legally permitted in all United States jurisdictions.

Polls show that most of the general population is in favor of physician-assisted suicide, but clinicians are more evenly split [64]. The Oregon experience has shown that patients who choose physician-assisted suicide are more concerned about loss of autonomy and loss of enjoyable activities rather than intractable pain or being a financial burden on the family [65]. No matter the legal jurisdiction, physicians should be prepared to address the underlying concerns of patients who might be considering physician-assisted suicide, including addressing fears of intractable pain, incapacity, loss of autonomy, and other concerns about end-of-life care that would prompt patients to approach physicians with such requests [66].

Palliative sedation

Palliative sedation, also known as terminal sedation, is the use of narcotics and high doses of sedatives to cause deep sedation in terminally ill patients to relieve pain and suffering that cannot be relieved with other palliative care measures that allow the patient to retain consciousness. Patients must have the decision-making capacity to choose this course and must express in advance of incapacity the wish to forgo life-sustaining medical treatment. Once this choice is made, the patient is sedated with barbiturates into unconsciousness. If a trial of palliative sedation is chosen, the patient is brought back to consciousness to see whether the sedation was ameliorative of the patient’s symptoms. If the trial of sedation is unsuccessful at relieving the patient’s symptoms, the patient is sedated again. Because of the sedation, patients are unable to ingest orally administered fluid and nutrition, and ultimately, death will occur from dehydration, lack of nutrition, or other intervening complications [58,67]. This practice is ethically defensible and although some ethicists do not find a moral distinction between palliative sedation and euthanasia because both result in the death of the patient [68], the United States Supreme Court recognized that the use of strong palliative care measures that may result in unintentional death are acceptable under the principle of double effect [53,54]. There is an ethical controversy as to whether a trial of palliative sedation should be attempted in certain patients before continuing the procedure to determine whether the palliative sedation will continue to relieve the symptoms once the patient regains consciousness. Another ethical controversy arises in determining which symptoms of pain and suffering should reach the threshold of intractable pain such that palliative sedation is the only effective treatment. Certainly, intractable physical pain should qualify as appropriate for palliative sedation, but more controversial is the attempt to quantify the type and level of suffering that should justify a response of palliative sedation. So-called
“existential suffering” (ie, the suffering that results from meaninglessness or lack of joy in activities of daily living for patients at the end of life) is more difficult to justify as warranting palliative sedation.

Futility (patient or surrogate demands for inappropriate life-sustaining medical treatment)

Many of the ethical issues of limitation of treatment in end-of-life care are those in which the patient, surrogate, or family asks to have life-sustaining medical treatment withdrawn. A more recent and difficult ethical issue arises when the physician’s evaluation is that life-sustaining medical measures would no longer be appropriate, but the patient, surrogate, or family maintain that the physician must “do everything” to treat the patient. Although physicians must be careful not to confuse quality-of-life issues with the evaluation of the effectiveness of treatment, physicians should have the ability to determine when medical measures would be ineffective. Though there are critics of the concept, and use of the term “futility” and legal precedent is sparse, ultimately, at some point in end-of-life care, medical treatment will no longer be effective [69–71]. Physicians should have the ability to determine medical ineffectiveness with proper procedural safeguards (including a second opinion and offer to transfer if another physician willing to treat can be found) [72]. Some medical organizations have recognized the ethical propriety of determinations of futility in specified circumstances [73], and the Texas legislature has codified a procedural approach with due process and safeguards for such conflicts [74].

Ethics committees and their role in limitation of treatment

Ethics committees can be a helpful source of advice through consultation and deliberation about ethical issues in limitation of treatment. Ethics committees are comprised of individuals with various expertises who may be able to lend critical knowledge and skills to the resolution of issues in end-of-life care [75–77]. Health care institutions are required by the Joint Commission on the Accreditation of Healthcare Organizations to have a mechanism for the resolution of ethical issues, and ethics committees have been recognized by courts as having a legitimate role in end-of-life care decision making [17].

Summary

Most United States patients die while under medical care, and decisions need to be made about the appropriate use of medical technology for patients when further treatment toward the goal of a cure is no longer appropriate. Cardiopulmonary resuscitation, ventilation, nutrition and hydration, dialysis, transfusions,
and antibiotics are part of the technological armamentarium of physicians that should be applied and withheld or withdrawn with attention to appropriate medical and ethical circumstances. Treatment may be ethically and legally limited by withholding or withdrawal based on patient wishes, agent or surrogate authority, or careful physician determination of ineffectiveness.

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[49] Bush v Schiavo, Case No. 2D03–5783 (Fla Ct App 2d Dist 2004).


[71] Gilgannon v Massachusetts General Hospital, SUVC92-4820 (Mass Super Ct, Suffolk Co, April 21, 1995).


