

Palliative Treatments of Last Resort: Choosing the Least Harmful Alternative

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Comprehensive palliative care, as exemplified by many state-of-the-art hospice programs, is the standard of care for the dying. Although palliative care is very effective, physicians, nurses, patients, families, and loved ones regularly face clinically, ethically, legally, and morally challenging decisions throughout the dying process. This is especially true when terminally ill patients are ready to die in the face of complex, difficult-to-treat suffering and request assistance from their health care providers. Although physician-assisted suicide has received the most attention as a potential last-resort response, this practice remains illegal in the United States except in Oregon, and even there it is relatively infrequent. More commonly, decisions are made about accelerating opioid therapy for pain, forgoing life-sustaining therapy, voluntarily stopping eating and drinking, and administering terminal sedation in response to unacceptable suffering. The moral distinctions between these practices are critical to some but relatively inconsequential to others. This paper illustrates, through summaries of real clinical cases, how each of these practices might be used in response to patients in particular clinical circumstances, keeping in focus the patient's values as well as those of families, other loved ones, and health care providers. The challenge is to find the least harmful solution to the patient's problem without abandoning patients and their loved ones to unacceptable suffering or to acting in a more deleterious way on their own.

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Comprehensive palliative care, which includes pain and symptom management, support for patient and family, and the opportunity to achieve meaningful closure to life, is the standard of care for the dying (1–8). Any intervention that is likely to hasten death should be considered only as a last

resort, when life has become intolerable to the patient in the face of unrestrained efforts to relieve suffering (9). In the United States, it is agreed that patients should receive sufficient treatment of their pain (1–8), even at doses that risk hastening death, and that patients have the right to forgo life-sustaining treatment, even if their purpose is an earlier death (10–15). Recently, terminal sedation and voluntarily stopping eating and drinking have been proposed as legally acceptable alternatives to physician-assisted suicide for persons whose suffering cannot be addressed by standard pain management and cessation of life support (9, 16–23). Outside of Oregon (24, 25), physician-assisted suicide remains illegal in the United States, although a covert practice exists in the rest of the country (26, 27). Because any of these acts could result in a hastened death, their moral and clinical evaluation should always consider the clinical context, the proportionate degree of suffering, the inadequacy of less drastic alternatives, and the nature of the decision-making process (9).

When a patient expresses the wish to die, exploration of the adequacy of palliative care should begin, including assessment of pain management, depression, anxiety, family burnout, and spiritual and existential issues (28–31). For patients who are genuinely ready to die, for whom suffering is intolerable despite comprehensive palliative efforts, an exploration of methods for easing death can begin. The methods will be determined by the patient's clinical situation; the values of the patient, family, and physician; and the status of current law. The **Table** outlines current methods that may hasten death. The first four options can be practiced openly, with good documentation and consultation, whereas the latter must be carried out covertly, except in Oregon (24, 25). Clinicians faced with these difficult decisions should be aware of all of these options, including their indications, risks, benefits, and likely outcomes, and how to discuss them with patients and families.

We present relatively straightforward clinical synopses of actual cases to illustrate how and when each of the interventions might be chosen. Each scenario is followed by a brief clinical commentary, with references for those who want to learn more about the legal, ethical, and policy implications and

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Table. Last-Resort Palliative Interventions

Intervention*	Certainty of Death	Patient Competence	Physician Involvement	Legal Status	Ethical Consensus
Standard pain management	Uncertain and unintended by patient or physician	Not required	Necessary	Legal	Yes
Forgoing life-sustaining therapy	Certain if dialysis is forgone; uncertain if ventilation, feeding tube, steroids, or insulin is forgone	Not required	Usually necessary	Legal	Yes
Voluntarily stopping eating and drinking	Certain, but requires time and discipline	Required	Desirable but not necessary	Legal	Growing consensus on its acceptability
Terminal sedation: heavy sedation to escape pain, shortness of breath, other severe symptoms	Certain if fluids are withheld (the standard practice)	Not required	Necessary	Legal	Growing consensus on its acceptability
Physician-assisted suicide†	Uncertain (patient may not take medication at all or not take as directed; medication may not work)	Required	Necessary for prescribing, unnecessary for administering	Illegal in all but one U.S. state, but unlikely to result in prosecution	No consensus on acceptability but has considerable public support
Voluntary active euthanasia	Certain	Required	Necessary	Illegal and likely to be prosecuted	No consensus on acceptability

* Options are listed in order of increasing legal and ethical uncertainty.

† We use the term "physician-assisted suicide" for clarity because of its widespread use in the medical literature, but we do not believe that the term "suicide" accurately reflects the meaning of this action, nor does it necessarily differentiate this practice from other last-resort practices. Technically, the last four practices might be considered suicide in the sense that death was sought by the patient as the only means of escaping intolerable suffering. However, the term "suicide" also connotes an act of self-destructiveness by a person with mental illness, whereas in each of these cases, death was viewed by the patients as a form of self-preservation. We must ensure that politicized public discussion about the legalization of physician-assisted suicide does not lead to distortion of the issues and ultimately to uninformed decision making.

controversies. Knowledge of the availability of these options can be valuable to patients who have witnessed a bad death and fear a similar experience. Most persons will not request assistance in hastening death if they receive state-of-the-art palliative care, but some want to know that the potential for escape exists. Knowledge of the range of possibilities can also help clinicians better respond to the relatively rare patients whose pain and suffering become intolerable, without violating their own values and without abandoning their patients. Clinicians who care for severely ill patients must become aware of these options and decide which ones they are willing to provide as a last resort (9). The challenge is to find the least harmful alternative given the patient's circumstances and the values of the patient, family, and clinicians involved.

Clinical Examples of Last-Resort Interventions

Standard Pain Management

A 68-year-old man with metastatic small-cell lung cancer had excruciating bone pain and was near death. He initially responded to a combination of radiation and chemotherapy and had a 3-year remission. When his disease recurred 4 months ago, he chose a palliative approach. His pain from extensive bony metastases was initially well controlled with high-dose, around-the-clock opioids supplemented by radiation and nerve blocks. He prepared for death through talks with his family and clergy, and he felt that he had no remaining "unfinished business." At that time, he weighed 80 pounds, he was bed-bound, and his

pain averaged 8 points on a 10-point scale. He did not want to die but was willing to accept the risk for earlier death that might come from further increasing doses of opioids. After a palliative care consultation, his physician increased his total opioid doses by 25% per day until the pain was adequately controlled, or, if sedated, he appeared comfortable.

On the third day, the patient became very sleepy but arousable and appeared relatively free of pain. The physician shifted an equianalgesic amount of opioids from oral to transcutaneous administration because the patient was unable to reliably swallow. The patient became unresponsive but appeared comfortable, and he remained in that state until he died 2 days later.

Commentary

Standard pain management has wide social acceptance by medical, legal, and religious groups and the public (1–9). For most of his illness, this patient's pain was well controlled with high-dose opioids, and he was fully alert and functioning. When his pain increased toward the end of life, both patient and physician were willing to risk an earlier death as an unintended side effect, but it was neither a hidden nor an explicit purpose. The patient's suffering was proportionately severe enough to warrant taking the risk. Therefore, this action was consistent with the rule of double effect (32). Had the patient's or the clinician's intent been to hasten death, it would be more difficult to use this rule to justify such treatment (23). Although good pain management can usually be achieved without sedation and without shortening life, sometimes a patient's pain is so severe or the patient is so frail that

the risk for accelerating death is real. When the patient in the above case study lapsed into a sedated state, the dose of opioid was neither increased nor decreased, and the side effect of sedation was accepted as proportionately necessary to control his pain.

Withdrawal of Life Supports

A 56-year-old man developed a malignant brain tumor 3 years ago. He initially responded to a combination of surgery, radiation, chemotherapy, and corticosteroids. Although his cognitive abilities were diminished so that he could no longer work as an accountant, his altered brain unleashed new creativity in his hobby of painting. Later, when his tumor began to rapidly grow, he developed terrifying seizures during which he felt paranoid, confused, and attacked. During his seizure-free times, he talked in earnest about being ready to die. He was treated with anticonvulsants and antidepressants, with little relief. He tried unsuccessfully to end his life by jumping into Lake Ontario in winter; as a result, he was kept under 24-hour supervision for being "suicidal."

The patient's physician subsequently realized that dexamethasone therapy was probably prolonging his life and that the patient could choose to discontinue it. After ethics and palliative care consultations, it was decided that it was both morally acceptable and clinically appropriate to provide this option to the patient, who immediately refused further dexamethasone. Within 12 hours, the patient went into a deep coma (probably from a combination of brain swelling and iatrogenic adrenal insufficiency). He had no pain or agitation and died peacefully 24 hours later.

Commentary

The patient's right to refuse life-sustaining treatment, or to stop it once it has been started, has wide legal and ethical acceptance (10–15). This right holds even if the patient wishes to die but could live indefinitely with treatment, provided that the patient is fully informed about the alternatives and has the mental capacity to understand the decision. Families can generally make these decisions on behalf of a patient who has lost mental capacity, provided there is a clear consensus that such actions reflect the patient's values, previously stated wishes, and best interests (14). Because these decisions frequently result in the patient's death, clinicians should be forthright about evaluating such requests and carefully assess the patient's mental capacity, information about all palliative care alternatives, and the proportionate presence of suffering. This particular patient's wish to die was labeled as "suicidal" until it was realized that he was within his rights to stop life supports. This realization allowed a more open-minded conversation between patient,

family, physicians, and the health care team than was previously possible.

Voluntarily Stopping Eating and Drinking

An 83-year-old woman was admitted to a nursing facility 1 year after experiencing a major cerebrovascular accident that left her with a dense hemiparesis but retained cognition. She stayed at home for the first year after her stroke with extensive support from her family and the visiting nurse service, but her skilled nursing needs eventually increased to the point that care at home was too difficult. Her other chronic medical problems included degenerative joint disease, osteoporosis, and coronary artery disease.

Six months after the admission, after extensive discussions with her family, her doctor, and clergy, the patient stopped taking all medicines other than pain relievers and adopted a purely palliative approach. Her care at the nursing facility was supplemented by a hospice team. Her goal was to achieve a quicker end to what had become for her an interminable dying process. She initially felt elated by the decision and began saying good-bye by telling her life stories to her family in tape-recorded interviews. After 3 months of meaningful preparation, she had told all her stories, and her condition had again stabilized in what she viewed as a very poor quality of life.

The patient then began talking in earnest about wanting to die. Being a life-long Unitarian, she had no personal moral objection to voluntarily hastening death, but she refused to compromise anyone in her family or her physician, given the current state of the law. She read a newspaper account of a woman who had chosen to stop eating and drinking (33), and immediately began exploring this option with her family and physician. Her family initially worried that it would be a long, painful process, but her doctor found some reassuring data about patients with cancer who died in this way (34). Several staff members were unable to accept her choice and were reassigned to other patients.

As the process unfolded, her family visited every day in rotating shifts. The patient was initially very talkative and had a special word for each of her children and grandchildren. On day 6, she became sleepy and intermittently confused. The nursing staff kept her mouth moist and her skin well moisturized with lotion. Her favorite music played constantly in the background. The staff was prepared to provide sedation if she became agitated or clearly uncomfortable, but this proved unnecessary. She was in a coma for the final 3 days of the 15-day process.

Commentary

Voluntarily stopping eating and drinking usually leads to death within 1 to 3 weeks (9, 19–21). Because the physician's role is indirect (ensuring an

informed decision and awareness of palliative care alternatives, then addressing uncomfortable symptoms), this process does not require a change in the law. Because stopping eating and drinking is viewed as a variant of stopping life-sustaining treatment, it is in theory available to persons who do not have imminently terminal conditions. The process initially requires self-discipline and cooperation from family and health care providers. The substantial delay between initiation and death may be prohibitive for some patients with severe, immediate symptoms. Patients may also face additional challenges from symptoms that occur as the process unfolds. However, many patients who fear prolonged suffering and lack of choice find this possibility reassuring because it does not necessarily require “permission” from health care providers. In fact, especially if the patient is in a health care institution, the team must agree at a minimum not to interfere. Ideally, clinicians participate in the initial evaluation and then palliate symptoms throughout the course.

Terminal Sedation

A 35-year-old man had had AIDS for more than 10 years. He had been near death several times over the past 5 years and had been in an AIDS hospice at the time when protease inhibitors became available. With the addition of protease inhibitors to his therapeutic regimen, the patient overcame recurrent infections and severe wasting and felt robust, gained weight, and returned to his work as a designer for 2 years. However, over the next 9 months, his disease again began to progress in spite of numerous adjustments to his medication dose. He started losing weight, developed AIDS-related enteropathy, and began to lose his sight because of long-standing cytomegalovirus retinitis. This time, despite numerous changes in his anti-retroviral regimen, he experienced no reprieve. The patient was again admitted to a residential hospice. He was very fearful of AIDS dementia and wanted to be reassured that he could be sedated if he became severely confused or agitated.

The patient's initial time in the hospice program was comfortable and meaningful because he had healing contact with family, friends, and clergy. As death approached, he developed high fevers, rigors, and increasing shortness of breath. These symptoms were treated with a morphine infusion and acetaminophen, but no medical workup was done and no antibiotic treatment was given. As the dose of morphine was increased to try to relieve his symptoms, the patient became delirious and agitated. When the dose was decreased the patient became more lucid but was very uncomfortable. He asked his doctor to help him escape from his agony. The doctor offered to sedate him to the point of unconsciousness and then withhold further treatment, including intravenous fluids. The

patient was reassured that the sedative dose would be increased until he appeared to be resting comfortably and that it would not be cut back until he died. The health care team, the patient, and his family reached the consensus that this was the best of the available options. It would allow the patient to achieve the death that he wished for without violating the law or forcing him to suffer unnecessarily. He was given a midazolam infusion that was titrated upward until he achieved a sedated state and was then maintained at that level. He died within 24 hours.

Commentary

Terminal sedation has been proposed as an alternative to physician-assisted suicide for terminally ill patients with severe symptoms. This method does not require changes in the law (9, 16–18). The patient is sedated to unconsciousness to relieve severe physical suffering and is then allowed to die of dehydration or some other intervening complication. Terminal sedation is ethically considered to be a combination of aggressive symptom management (sedatives to treat unbearable symptoms) and withdrawal of life-sustaining therapy (fluids, nutrition, and other treatments). When considered as an aggregate act, terminal sedation may be more morally complex and ambiguous than is generally acknowledged (9, 22, 23, 35), but many persons who adamantly oppose physician-assisted suicide find this practice acceptable (36, 37). The practice differs from euthanasia in that the dose of medication is maintained but not increased once sedation is achieved and no subsequent intervention to accelerate death, such as the introduction of a muscle-paralyzing agent, is given.

Terminal sedation allows health care providers to respond to a much wider range of suffering than would physician-assisted suicide even if it were legalized, because the latter would be restricted to competent terminally ill patients who are capable of self-administration. Terminal sedation has been used to respond to troubling syndromes such as terminal delirium, in which patients lose mental capacity at the end of life. The sedation itself is a mixed blessing—the patient is unaware of suffering but spends his or her last days in an iatrogenic coma. The facts that terminal sedation is not immediately lethal and requires a team to administer it are felt by some to be important safeguards. Guidelines for the practice of terminal sedation have been proposed (17), but little is known about actual practice patterns.

Physician-Assisted Suicide

A 59-year-old man received a diagnosis of oropharyngeal cancer 2 years ago. Because the tumor was too large to be resected, the patient was treated with che-

motherapy and radiation. He was relatively asymptomatic for 1 year, during which he worked at his usual job. His tumor recurred inside his mouth and in his neck, making it hard to swallow his secretions. His initial goal was to live as long as his symptoms could be adequately managed and then to die as quickly and painlessly as possible. He was particularly afraid of suffocation, which he had seen in a coworker who died of emphysema. His pain was well controlled with around-the-clock administration of sustained-release morphine. After exploring his options, he was admitted to a home hospice program.

The patient's time on hospice was very meaningful, with regular visits from members of his church congregation, friends, hospice nurses, aides, and volunteers in addition to his family. Unfortunately, his tumor eventually began to bleed profusely inside his mouth and outside his neck. He was terrified of suffocating and bleeding to death. He asked for enough barbiturates to "put me out of my misery." He considered stopping eating and drinking but felt the wait for death would be too long given his acutely deteriorating condition. He was offered terminal sedation so that he could escape his suffering, but he remained fearful of bleeding and suffocating but not being able to tell his caregivers about his subjective state. He was also worried about the impact that watching him bleed to death would have on his family. His family understood and accepted his decision and was willing to support him in the process if the physician would provide a prescription for barbiturates. After discussing the situation with his practice partners, the physician reluctantly but knowingly provided him with a lethal amount of barbiturates in a prescription ostensibly intended for insomnia. That evening, the patient took the entire amount with his family present, went into a deep sleep, and died quietly. Because the practice was illegal, the patient's final events were not documented.

Commentary

This patient chose physician-assisted suicide because other last-resort options could not satisfactorily address his particular situation (8, 9, 24–27, 38–40). After a long period of excellent palliation, this patient's symptoms intensified greatly as death approached. Voluntarily stopping eating and drinking would not act quickly enough to respond to his particular clinical circumstances. Terminal sedation was also possible, but he feared suffocating while sedated and being unable to alert his caregivers of his distress. He was also concerned about the impact on his family were he to bleed to death while sedated. The physician, after having a private conversation about the clinical situation with his colleagues, reluctantly provided a prescription for barbiturates that could hasten death if taken all at once. Because of fear of legal action, the physician

was not physically present to respond to complications but was available to the family by phone should problems arise. Maintaining the patient in a terminally sedated state was the physician's backup plan, but the patient died without complications.

Discussion

Although the case studies presented here portray clear distinctions among the five last-resort interventions, in practice both the clinical indications and the practices may blur. Categorization may depend on specific circumstances and may be subject to interpretation. For example, the distinction between terminal sedation and voluntary active euthanasia is based in part on whether the dose of sedative is maintained or increased once sedation is achieved and whether a lethal injection is given. In some western traditions, it is also based on the physician's intent to hasten death, which is subjective and never absolutely knowable (22, 23). Reasonable observers might differ in their categorization of terminal sedation in terms of intent (9, 35). Similarly, what begins as voluntarily stopping eating and drinking in an alert, capable patient may become withholding life support from an incompetent patient as obtundation occurs. If the patient subsequently becomes delirious in this terminal phase, this practice might have to be followed by terminal sedation. Experienced clinicians could easily think of other complex examples in which the health care team and the family might be very challenged to find an adequate approach.

Each of these interventions, alone or in combination, may have a small place in end-of-life care for severely ill patients in whom the usual palliative treatments are failing. Only in the standard pain management case was death clearly unintended by both patient and physician—the risk of death was understood given the patient's grave condition, but it was not the goal of either party. Death was sought by the patient who stopped dexamethasone therapy, but it was not a certainty. With the other three interventions, death was the inevitable outcome and was actually sought by the patients. Although the physician's purpose in participating in these alternatives is to respond to human suffering, the decision-making process should include acknowledgment that death is inevitable. In any and all of these interventions, the physician must ensure the adequacy of palliative care and a full exploration of alternatives, the patient's mental capacity, and the proportionate presence of suffering.

Standard pain management and stopping life-sustaining therapy are standards of care, and all clinicians should be willing to provide these options.

Even though voluntarily stopping eating and drinking and terminal sedation are legal, they are more extraordinary options, considered only when no acceptable alternatives are available and both patient and physician consider participation to be moral. Physician-assisted suicide remains illegal in most states. It should be exceedingly rare and provided only on request from the terminally ill patient whose suffering is intolerable and only when other alternatives are inadequate or incompatible with the patient's fundamental values. When physicians unilaterally choose not to participate in these options, they are obligated to search for acceptable alternatives with the patient. Ethics and palliative care consults may be helpful. If a mutually acceptable approach cannot be found, the patient and family should be given the option of transferring care to another physician.

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