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Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects

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Patients with advanced illnesses sometimes request that physicians help hasten their death. Increasingly in North America and Europe, legal options allow physicians to perform this role. Among death-hastening options, the spotlight has been on physician-assisted death. However, voluntarily stopping eating and drinking (VSED) is also a course that patients may choose. Although VSED theoretically does not require physician involvement, clinician participation is critical in terms of initial assessment and ongoing management. In this review, we examine both clinical issues in assessing patients who are considering VSED and the clinical challenges that may emerge during VSED. We also explore some of the underlying ethical and legal considerations for physicians who either care for or decline to care for these patients. Physicians who care for seriously ill patients should be prepared to respond to patients' requests to participate in VSED.

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Palliative care and hospice remain the standards of care to relieve suffering of and provide support to seriously ill patients.[1] Palliative care can be delivered alongside disease-directed medical treatments, whereas hospice includes a system of care devoted to comfort and dignity for patients no longer receiving life-prolonging treatments.[2,3] Palliative care, however, has limitations. Studies have demonstrated a small percentage of "tough cases" in which unacceptable quality of life, or fears of future suffering, persist despite unrestrained efforts to palliate.[4] These patients may inquire about options to hasten death.

The prolonged debility and dependence that can accompany the dying process is intolerable to some patients who would prefer to forego its late stages.[5] Many patients would like to exert as much control as they can over their deaths. Some, particularly those with progressive neurological diseases, may ask their physicians about pursuing death-hastening choices preemptively, worried that their disease will rob them of the cognitive or physical abilities later required to carry out these choices.[5]

Although many patients inquire about their future possibilities to hasten death, a smaller number reach a point where they want an escape *right now*.[6] The first step in responding is a thorough assessment of the biological, psychosocial, and spiritual suffering underlying the patient's request.[5] The clinician should explore the patient's fears and distress, and honestly explain what can and cannot be promised.[7,8] The clinical team should redouble palliative efforts to address the patient's concerns. If the patient remains interested in "last resort" options, the clinician should discuss which are legally available and which the clinician can support personally.[9,10] Patients who know their options may face their futures with less fear. Many will not pursue these options because they adapt to the limitations imposed by their illness. But if efforts to palliate are not effective, and the patient's request makes sense to the clinician, then the challenge will be to find common ground, if possible, within the options outlined in the **Table**.

Voluntary stopping eating and drinking (VSED) has some clinical advantages as a "last resort" option.[9,10] The **Box** provides a case example; the case is real, with deidentification so that the person is not identifiable. From initiation to death, VSED has a distinct time frame for patients and families to come together, "say goodbye," and work on life closure issues. The initial states of VSED are largely under the patient's control; clinicians are needed to assess the patient and to help manage symptoms. The bulk of the process, however, is patient driven and executed. Even in states with legalized physician-assisted death (PAD), VSED is an option when PAD is not morally acceptable or for patients who are not yet terminally ill.

Table. Options to Potentially Hasten Death

Potential Last Resort Option	Current Legal or Ethical Status in United States and Canada
Medications such as opiates for severe pain/dyspnea used proportionately	Legal and ethically accepted
Stopping or not starting life-sustaining therapy	Legal and ethically accepted
Palliative sedation, potentially to unconsciousness	Legally accepted Ethically controversial if patient or physician's intention is to hasten death
Voluntarily stopping eating and drinking	Not illegal; legality not tested Ethically controversial
Physician-assisted death (aka physician-assisted suicide or medical aid in dying)	Legal in 6 US states; all of Canada Illegal in >30 states and uncertain in others[11] Ethically controversial
Voluntary active euthanasia	Illegal in all US states Legal in Canada Ethically controversial

Box. Case Presentation

An elderly man with widely metastatic cancer refractory to treatment was seen in palliative care consultation. He was referred for hospice care, and a commitment was made to maximize his quality of life. He asked about potential access to physician-assisted death in the future (which was not legal in his state of residence). He also inquired about other potential legally available options to end his life should his suffering become unacceptable, and he was made aware of the possibility of voluntarily stopping eating and drinking (VSED). He initially perceived this prospect to be "barbaric," but, given his limited options, he learned more about it.

Several months later he developed multiple, painful fractures in both legs such that he could no longer walk. He was admitted to the palliative care unit, and wanted to discuss current options for hastening his death. He had full decision-making capacity. His pain was controlled when he was still but became severe with any movement. Although his clear preference was physician-assisted death, after a thorough assessment, including ethics and psychiatric consultations, he began VSED and died relatively peacefully 10 days later.

VSED also has disadvantages. The process takes too long to effectively respond to those with severe immediate physical suffering. Other options (Table) would be preferable under those circumstances. VSED works best for disciplined, resolute individuals who can resist drinking despite thirst. VSED also requires that caregivers provide support and help manage symptoms as VSED progresses. Surveys suggest that hospice professionals are substantially more accepting of VSED than PAD.[12] Many hospice programs will support VSED for patients already enrolled, but they may delay enrolling new patients who wish to start VSED until several days after the process is initiated if they otherwise would have a life expectancy of greater than 6 months.[13]

Unlike other "last resort" options, VSED theoretically does not require direct physician involvement.[9,10] In practice, however, clinician participation is critical in terms of both initial assessment and ongoing management. Key aspects of assessment are to ensure that the patient has decision-making capacity, the decision is not influenced by a mental illness, the patient is fully informed of the risks and alternatives, and the choice is voluntary. Patients should understand that their physician may have erred in diagnosis or in prognosticating disease trajectory.[14] There should be a thorough discussion of other alternatives, including intensified palliative care, stopping of life-sustaining treatments, and palliative sedation. Patients should understand that VSED may be difficult, suffering may worsen, and thirst may be hard to manage. Patients who initiate VSED should be counseled about the importance of not drinking even small amounts, which can indefinitely prolong the process. VSED generally lasts 10 to 14 days before death, but survival may vary depending on the underlying disease states, debility, and hydration.[15]

The late stages of VSED require substantial support from others; hospice care is generally recommended. A formal do not resuscitate–do not intubate (DNR-DNI) order should always be in place. A health care proxy should be appointed to make decisions on the patient's behalf because the patient will likely lose decision-making capacity in the late stages. The patient-proxy discussion should explicitly include the patient's future wishes about how caregivers should proceed if the patient develops delirium, forgets his or her goals, and then requests food or fluids.

Several mental disorders are associated with stopping eating, and more rarely, stopping drinking. Major depressive disorder is associated with desire to die, decreased appetite, weight loss, and dehydration. Patients with psychotic disorders may stop eating and drinking if they have paranoid delusions about being poisoned. Patients with depression and psychosis should receive mental health evaluation and treatment. Although mental health evaluation is mandated in some cases by US laws regulating PAD, such a requirement would be difficult to enforce for VSED when the role of the physician is supportive but not required. In addition, depression may be a confounding factor in end-of-life decision making, and determining if the choice is authentic to the individual or arises from treatable psychiatric conditions can be difficult.[16] Finally, patients with anorexia nervosa may die from malnutrition. Unlike patients pursuing VSED, however, such patients continue to drink fluids, are motivated by beliefs that they are overweight, and lack insight into the risk of death that their malnutrition presents.

Thirst during VSED is the most difficult symptom to manage. This symptom can be palliated to a degree by applying lip moisturizer and "swish and spitting" with an artificial saliva product (glycerin swabs are generally not recommended, and regular sips of liquids can prolong the process indefinitely). Early in the course of VSED, when the patient remains cognitively and decisionally intact, the experience of thirst may prompt a patient to decide that he or she no longer wants to pursue VSED.

A more difficult situation occurs later in the course of VSED when patients become delirious, lose decision-making capacity, and may repeatedly request fluids. The patient and his or her health care proxy should have already discussed and carefully documented the patient's wishes for this situation. Some patients may stop such requests in response to reminders of their goals and prior statements, along with efforts to intensify mouth care. Plans for aggressively managing delirium should be considered in advance by the patient, family, and the health care team. Medications used in hospice to treat adverse delirium experiences (eg, benzodiazepines and/or antipsychotics) should be available, and may blunt the discomfort of thirst.

If a patient with delirium repeatedly forgets his or her goals and requests to drink, caregivers may find it challenging not to provide fluids even if there was an initial agreement. Caregivers and surrogate decision makers should be forewarned about the difficult balance between supporting the patient's goals, when they previously had decision-making capacity, and not coercing the now incompetent and suffering patient. On the one hand, it would seem unethical to withhold oral fluids from a confused, thirsty patient who persistently requests to drink. On the other hand, patients may be upset when they drink fluids, the delirium clears, and they find their plan did not work. Some patients who have died from VSED only did so after trying it several times. Formal ethics consultation should be obtained in these difficult cases.

Ethical Issues

Even those within the medical community who oppose VSED may agree that if a competent patient's decision to engage in VSED is

voluntary and not resulting from a mental illness, the physician is morally and legally required to respect it.[17] And although some patients will choose VSED because of anatomical or neurological impairments that make swallowing painful or even impossible, most choose VSED with the specific intention of hastening their death. The most salient areas of controversy are (1) whether suicide is always morally wrong; (2) whether VSED is chosen voluntarily; and (3) whether clinicians who believe that suicide is morally wrong have an obligation to participate in the care of patients who choose VSED, or even whether they have an obligation to inform patients of this option.

Is Suicide Morally Wrong?

Some believe that it is always morally wrong for a person to hasten his or her own death, and therefore efforts should be made in all cases to prevent this.[18] Others argue that, under some circumstances, suicide may be a decision that patients with decision-making capacity should be allowed to make.[19] Although suicide harms a person by causing that person to die, it may be rational if the act is necessary to protect that person from what they perceive to be a greater harm.[20] In circumstances where a patient with decision-making capacity and without a mental disorder determines that the harm of death is less than the harm of continued existence with physical or existential suffering, then the person's choice may not be morally wrong.

VSED and Voluntary Choice

One of the ethical pillars of medical decision-making is the requirement that the patient's choice be voluntary. VSED stands out from many other decisions that arise at the end of life because it does not involve a discrete act that may be performed by another, such as withdrawal of a life-sustaining treatment or prescription of a lethal drug. VSED requires a sustained determination of the patient's own will despite substantial discomforts such as thirst and hunger. Furthermore, decisions to undertake VSED can be reversed by the patient, at least in the early phases. Among other "last resort" decisions, VSED raises the fewest concerns about whether the choice is voluntary. Assessing voluntariness may become more difficult when the patient loses decision-making capacity in the course of VSED.

The Role of Physicians in VSED

There are 2 diametrically opposed views about the role of physicians in VSED. One view holds that there are no relevant ethical distinctions between palliative care for managing the symptoms associated with VSED and other situations where palliative care is desired.[21] The argument is that physicians have an obligation to provide palliative care for all those who need it, regardless of the source of their suffering. Even some who express concerns about VSED agree that physicians "may be morally required to provide the patient who engages in VSED with appropriate medication for treating the pain and suffering that can accompany the refusal of hydration and nutrition."[17(p62)22]

The other view holds that VSED is immoral because suicide is immoral, even when it seems to be rational.[18] Although suicide cannot always be prevented, some believe that failing to try to prevent or assisting a suicide is always morally wrong. In this view, clinicians who facilitate this act by not persuading the patient to eat and drink, by managing the symptoms of VSED, or by providing sedation, are assisting in the act of suicide, both morally and legally.

A corollary to this debate is whether physicians have an obligation to inform patients that VSED may be an option for end-of-life care. Opponents argue that that physicians "only have a duty to provide information about treatment options to their patients if their patients have a right to be informed of this information," and that patients generally do not have such a right, since "(t)he option to engage in VSED is not, at least currently, part of standard care offered to patients at the end of life."[17(p72)] They argue, furthermore, that a "physician should not even mention this practice to the patient because, by doing so, the patient may be tempted or influenced to choose it." The physician would then be "advising, assisting, or tempting others to engage in wrongdoing."[18(p848)] Proponents counter that physicians have obligations to inform patients of all potentially relevant treatment options, and that discussion of VSED does not necessarily need to be persuasive, imply an endorsement, or be interpreted as a suggestion that the patient's life is not worth living.

Legal Issues

Clinicians in the United States often perceive the legal risks entailed with some end-of-life treatment options to be greater than they actually are.[23] The perception of risks associated with VSED may be especially high. Not only are there few on-point precedents but also there is a lack of judicial, legislative, and administrative guidance. Consequently, clinicians may be reluctant to advise, counsel, or otherwise be involved with VSED. Nonetheless, we are unaware of any cases in which a physician has been subject to disciplinary, criminal, or civil sanctions related to his or her involvement in VSED. Although extremely limited, all the available judicial precedent supports physician participation in VSED.[24-26] Moreover, many state health care decisions acts define "health care decisions" broadly enough to include VSED.[27] Clinicians cannot eliminate this legal uncertainty; they can, however, reduce it by meticulously documenting: (1) that all other reasonable options have been discussed with the patient, (2) that reasons for the request have been carefully explored through counseling, (3) that the patient has capacity and the decision is voluntary and not based in mental illness, and (4) that the patient has provided informed consent.

The legality of VSED can also be deduced from broader principles and patient rights. The most relevant are the patient's right to refuse unwanted medical interventions[28] and the patient's right to refuse unwanted bodily intrusions.[29] Patients with decision-making capacity regularly make decisions to withhold or withdraw interventions, such as dialysis, cardiopulmonary resuscitation, antibiotics, mechanical ventilation, and artificial nutrition and hydration. Clinicians not only *may* (permissively) but also *must* (mandatorily) respect such decisions.[28] Patients have a right to refuse these interventions, and clinicians have a correlative duty to honor that refusal.

VSED looks different than other interventions that may be declined at the end of life. This is because eating and drinking by mouth seems natural and does not involve the technology that more familiar forms of life-sustaining treatments have in common. Nevertheless, VSED usually occurs in a context that makes it a "health care decision." It is usually part of a broader treatment plan supported and supervised by health care professionals.

There is usually a medical role in palliating symptoms. Some health care associations, including one in the United States and one in the Netherlands, have issued guidance on how to care for patients who choose VSED.[30-32] For example, a 2017 position statement from the American Nurses Association[30] states: "the acceptance or refusal of clinically appropriate food and fluids, whether delivered by oral or artificial means, must be respected, provided the decision is based on accurate information and represents patient preferences.... This is consistent with ANA's values and goals of respect for autonomy, relief of suffering and expert care at the end of life." Thus, eating and drinking could be seen as falling within the scope of "health care" that patients have a right to refuse.

Patients with decision-making capacity also have a right to refuse not only medical interventions but also any bodily invasion. As William Rehnquist, the former Supreme Court chief justice, observed, one's bodily integrity is violated just as much by "sticking a spoon in your mouth" as by "sticking a needle in your arm."[23] Even if well intended, clinicians should not intentionally and nonconsensually touch a patient with decision-making capacity to feed them—if the patient considers feeding harmful or offensive.

All of these considerations notwithstanding, many clinicians still remain uncertain about the legality of VSED. Unlike the clinical and ethical aspects, the legal status of VSED is largely specific to each jurisdiction. Not only is there often an absence of explicit permission for VSED, but also there may be prohibitions on assisted suicide or neglect of a vulnerable adult.[33]

In every US jurisdiction, even in the 7 that have legalized PAD, it remains a crime to aid a patient to attempt suicide. There are 2 important distinctions, however. First, although the statutory language varies from state to state, many assisted suicide statutes, such as in Ohio, expressly exempt clinical interventions with "the purpose of diminishing the patient's pain or discomfort."[34] If the physician's role is limited to managing symptoms, that conduct may fall outside the scope of the prohibition against aiding suicide. Second, assisted suicide statutes typically target active methods, such as the use of guns or lethal drugs. In contrast, VSED does not involve the introduction of such a lethal agent. Instead, VSED entails the absence of eating and drinking.

Finally, some clinicians may be concerned that VSED constitutes neglect of a dependent or vulnerable adult. The conditions of participation for the Medicare and Medicaid programs require long-term care facilities to offer residents "sufficient fluid intake to maintain proper hydration and health."[35] State regulations, such as in New York, impose similar requirements on health care institutions.[36] Both federal and state laws, however, afford patients the right to refuse indicated treatments. Pursuant to these regulations, patients may voluntarily waive the provision of nutrition and hydration just as they have the right to opt out of default treatment by consenting to a DNR order.[35]

Conclusions

Voluntarily stopping eating and drinking is increasingly recognized as a means for seriously ill patients to intentionally hasten their deaths. Unlike other "last resort" options, the choice for VSED is, at least initially, almost entirely under the patient's own control. Patients considering VSED should be evaluated both to ensure adequacy of palliative treatments and to assess their decision-making capacity. Patients embarking on VSED will need expert palliative care to manage the associated thirst, and substantial caregiver support to respond to progressive debility. Although patient, family, and clinician participation in VSED is probably not illegal in the United States, its legality has not been tested, and it remains ethically controversial.

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