Background  Voluntary stopping of eating and drinking (VSED) is defined as a competent individual deciding to stop taking hydration and nutrition with the intention of hastening death. VSED is conceptually different from the loss of appetite and markedly diminished oral intake that occurs in the context of a progressing terminal illness, as well as diminished oral intake due to a psychiatric disease such as anorexia nervosa. Although controversial, VSED by terminally ill patients is seen by some as an ethical alternative to physician assisted suicide (PAS) (1) and will be discussed in this Fast Fact.

Epidemiology  How often VSED occurs is unknown. A few studies have tried to measure its prevalence, however all the data come from surveying clinician or caregiver recollection, which is subject to bias and overlooks the possibility that patients participate in VSED without a medical clinician ever knowing. In a hospice nurses, 40% recalled caring for a VSED patient (2). A review in the Netherlands estimated 2.1% of deaths were by VSED, although this is based on low-quality data (3). In one survey, Dutch physicians reported a median time from stopping eating/drinking to death of 7 days (4).

Symptom Burden of VSED  The little data that exist suggest that VSED is not associated with any unique end-of-life symptom burden. Pain, dry mouth, thirst, dyspnea, and agitation/delirium are commonly reported (2,3). Of note, hunger is not listed as a common symptom. Apart from being mindful to minimize unnecessary fluid administration via enteric elixirs or parenteral meds, symptom management is the same as with other dying patients.

Ethical, Legal, and Practical Concerns  • VSED is broadly considered to be different ethically and legally than PAS. While they have similarities, fundamentally PAS requires a physician directly assisting a patient hastening their death, whereas VSED can be completed without any clinician involvement or knowledge.
  • VSED in terminally ill patients is also considered by many to be ethically different than suicide. While individuals have a right to refuse medical treatment, this is not absolute, and a medically healthy individual who stops eating and drinking as a result of a psychiatric illness could be committed and have psychiatric treatment and medical nutrition forced upon them. This is because of society’s broad interest in protecting life, and the fact that many people, with adequate psychiatric care, will recover. VSED is different. First, many terminally ill patients participating in VSED are not psychiatrically ill – there is no ‘underlying mental illness’ to be treated. Additionally, confining and forcing artificial nutrition against the will of a terminally ill individual would be an extraordinary intervention of state power into a person’s life, for what is likely to be small benefit.
  • VSED is considered legal in the US. Several lower court decisions have been made in favor of a patient’s right to stop eating and drinking to hasten death (5), although there has not been a definitive higher court ruling. The American Nurses Association, the International Association of Hospice and Palliative Care, and the American Academy of Hospice & Palliative Medicine all consider VSED a legal option for terminally ill patients to hasten their deaths (6-8).
  • Not all agree, however. Given that VSED involves the expressed intention of hastening death, some ethicists argue that even limited clinician participation in VSED by providing counseling or managing symptoms is tantamount to assisting with an immoral act (hastening death) and thus should not be done (9,10). Others argue that while a clinician may judge VSED to be unethical, it is still important that clinicians continue to provide proper care and palliation for patients dying due to VSED (11).
  • In this context, clinicians should not underestimate how complex and challenging caring for a patient who is pursuing VSED can be. Health care organizations (e.g., nursing homes, hospice agencies) may not support a patient’s decision for VSED due to ethical or legal/regulatory concerns (12). Not all hospices will enroll patients pursuing VSED, especially if the patient would not qualify for hospice without VSED (e.g., a patient with a terminal illness, but who likely would live longer than 6 months if they continued eating) (12). Clinicians who want to support a patient pursuing VSED should be prepared that coordinating ethical, legal, and psychiatric input may be needed.

Responding to VSED Inquiries  See Fast Facts #156 and 159 which review the approach to requests for hastening death. Essentially, a clinician’s responsibility is to ensure that the decision is well-informed (based on accurate prognostic awareness); being made by a non-coerced patient with decision-making
capacity (including that the patient is not incapacitated by a severe psychiatric illness such as depression); and not stemming from treatable forms of suffering. Additionally, the clinician should engage the patient in a thorough discussion of what VSED looks like, including symptom burden, expected duration, and any alternatives available to the patient (cessation of potentially life-prolonging medical treatments, more aggressive symptom treatment, etc.). Given the significant cultural and emotional importance of eating and drinking, careful attention should be paid to the patient’s legal surrogate decision maker, family members, and other potential caregivers to provide education on VSED and to answer any questions. Patients should review and update any health care directive documents as well. When appropriate, clinicians should work to identify a hospice agency that will care for patients engaging in VSED. Like PAS, any clinician who feels that supporting a patient wishing to engage in VSED would be violating their professional ethic should excuse themselves from the patient’s care and refer them to a clinician who may be able to meet their need.

References

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