Voluntarily Stopping Eating and Drinking:
A debated exit strategy

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For if ethics implies an inquiry into what we are capable of doing or not doing, and into how the greater good may be achieved, then we need to explore further what it means when someone expresses the wish to die.

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Objectives

- Describe basic legalities and ethics of VSED as an option for the terminally ill
- Describe the process and outcome of VSED
- Explain the role of medical professionals in VSED
- Explore potential ethical, legal, and moral distress issues related to VSED

Disclaimer(s)

I am not a trained Bioethicist

I do not have a wealth of experience with VSED

I do have 20 years experience in Hospice and Palliative Medicine

Most ideal common end-of-life pathway

- Aged, a life well lived
- Diagnosis and subsequent determination of options in support of living
- Disease progression and functional decline with increase in focus on options to promote symptom management
- Hard conversations and engagement with Palliative care/Hospice care
- Primary focus on options in support of quality of life
- Natural progression of disease to debility, dependence, fatigue and a letting go. Including letting go of food and fluids.
- Terminal dehydration

Terminal dehydration

- The natural cessation of eating and drinking and/or decreased eating and drinking as disease progresses and the conversation that we have daily with families about what that means, how that feels, when that ends… is not VSED

Occasional alternative end-of-life journey

- Acute event involving urgent need to decide re: aggressive life-prolonging interventions to supplant failing organs
  - HD, vent support, ICU care, vasopressors/IVF/antibiotics, LVAD, etc.
  - PEG, NG
- Intractable pain, nausea/vomiting, agitation, anxiety/fear associated with decline
- Total dependence for care, loss of meaning, sense of hopelessness, feeling like a burden, loss of self
- Knowledge of common disease trajectory with fear of the above and desire to control timing and circumstances of death

"For many, the thought of an ignoble end, steeped in decay, is abhorrent"

Justice Brennan

Wish to hasten death (WTHD)

- As a hospice professional I consider that in my practice my **intention** is to neither prolong, nor hasten death specifically (disclaimer)
- **WTHD defined:** the WTHD is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death (Balaguer et al., 2016)

- PC response:
  - Explore the reasons behind the request
  - Intensify efforts to relieve pain and suffering to include full IDT support for psycho-social-spiritual suffering
  - Commit to non-abandonment
  - Seek mutually acceptable solutions for the patient's suffering (Swartz, 2014)

WTHD:
What legal exit options exist?

- In US, an individual with capacity or a designated decision-maker has the legal right to refuse medical treatment, even if life-sustaining
  - Well-recognized in American jurisprudence
  - Common-law principle of any **unwanted touching considered BATTERY**
  - Constitution as the **right to privacy** and consequently the right to be free from bodily intrusion
  - "70% of the 1.3 million Americans who die in health care institutions each year do so after a decision has been made and implemented to forgo some or all forms of medical treatment"
- **Principle of Double effect:** Accepting side-effect of sedation when high dose opioids are required to manage intense pain
- **Palliative Sedation to Unconsciousness:** 'lowering of patient consciousness using medications for the express purpose of limiting patient awareness of suffering that is intractable and intolerable' (NHPCO)
- MAID/PAD: available in some states

MAiD/PAD

Medical Aid in Dying/Physician Assisted Death

- Not the topic for today
- 8 states, DC, Maine (2020)
- Argument for: respect for autonomy, compassion for unremitting suffering, support of personal liberty, options when 'there is nothing to withdraw or refuse'
- Argument against: state's interest in preserving life; professional integrity 'do no harm'; potential for abuse

- All Acts say:
  - "Acts taken in accordance with law shall not for any purpose constitute suicide; assisted suicide; mercy killing or homicide."

And VSED:

Voluntarily Stopping Eating and Drinking

- When there is nothing to withdraw or withhold
- When pain and symptoms are controlled without being overly sedating
- When nothing meets criteria of intractable and intolerable
- Where PAD is not legal

- And suffering continues… what options exist

VSED: What is it?

- "an action of a **competent, capacitated person**, who voluntarily and deliberately chooses to stop eating and drinking with the primary intention to hasten death because unacceptable suffering persists' (Ivanovic et al., 2014)
- Voluntarily stopping eating and drinking (VSED) refers to a conscious and deliberate decision, by a **capacitated patient** suffering from advanced illness or an extremely debilitating medical condition, to intentionally refrain from receiving food or fluids by mouth, with the purpose of hastening death. (Pope et al., 2014)
- "entails deliberately ceasing the (self or assisted) oral intake of all food and fluids, except for those small amounts of fluids necessary for mouth comfort or for the administration of pain medications."

VSED: What it is NOT.

- It is distinguishable from the natural process whereby people in the final days or weeks of life lose interest in food or become unable to tolerate it physically.
- It also does not apply to individuals who are unable to take nourishment by mouth with or without assistance and who are dependent on artificial methods of nutrition and hydration.
- Finally, as the word "voluntary" indicates, it does not refer to the withholding of food or liquids from a capacitated person who actively desires food and drink. (Pope et al., 2014)

Who VSED?

- VSED is a decision taken by adult or older patients with severe disease, short life expectancy and dependency on others for everyday care….people physically able to take in food and fluids orally, but consciously unwilling to do so. (Bolt et al.,2015)

- "exit option for those… who are not dependent on medical technology, who are not terminally ill, and/or who are not in intractable pain… an option for people with severe forms of dementia, cancer that is not in the end stages, AIDS, quadriplegia, Huntington's disease, ALS, and other chronic illness. Some individuals with these conditions wish to hasten death before reaching end stages that they find heinous. This group of people would prefer to preserve dignity and independence, and to avoid altogether the pain and suffering associated with the end of life in these circumstances." paper

Why VSED?

- **21 reasons ranked**
  - Physical symptoms: pain, nausea, diarrhea, dyspnea, paralysis, pressure ulcers, edema
  - Psychological symptoms: depression, anxiety, delirium
  - Existential symptoms: meaninglessness of life, loss of control over self-care, loss of social role, becoming a burden/nuisance to others, hopelessness
- 79% report somatic reasons
- 77% report existential reasons
- 58% report dependence-related reasons (Rady et al, (2010)

"...being able to decide for oneself how and when one dies may be experienced as a form of self-determination, as preserving what little is left of the life he/she once had... suggests... may have more to do with self-preservation than self-destruction."

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VSED: Is it legal?

- Legal in all 50 states (to refuse treatment including nutrition)
- "The individual patient's right to engage in voluntarily stopping eating and drinking has long been recognized as an autonomous choice for patients with terminal illness."
  - JHPN 2019;vol 21;no 3
- The patient's option to voluntarily stop eating and drinking is grounded in the ethical principle of autonomy and is supported by statutory and case law
  - Miller and Meier 1998

VSED: Is it ethical?

- Grounded in ethical principles of autonomy
- Persons may refuse nutrition and hydration just as they may refuse other intrusions on their personal autonomy
- Is it suicide?
  - Suicide: the willful and voluntary act of a person who understands the physical nature of the act, and intends by it to accomplish the result of self-destruction. (Blacks Law Dictionary)
  - Common act of suicide is often violent and irreversible; generally irrational, with strong underlying emotional conflict, with a desire to hurt one's self and frequently devastating to those we love.
  - VSED is a generally well considered desire to avoid harm and self-destruction; a calm, peaceful living choice, that is reversible, and allows time for closure with those we love.
  - Both are legal, but carry very different weight

Does the right to VSED imply a clinician's subsequent responsibility to offer VSED under Informed Consent?

- **Informed consent:** permission granted in the knowledge of the possible consequences, typically that which is given by a patient to a doctor for treatment with full knowledge of the possible risks and benefits
  - the person giving consent must be of sufficient mental capacity and **be in possession of all essential information** in order to give valid consent.
- "Providers should educate patients that VSED is an available treatment alternative. Informed consent requires more than just acceding to a decision to refuse treatment. It also requires making patients aware of their end-of-life options."
- Potential for clinician's moral distress around offering VSED, as well as concern for legal implications around what some states legally refer to as 'basic' care.
- Knowing the option exists has been shown to relieve desperation, similar to those in states where PAD is legal, those that access the medication without ever ingesting it.

VSED: What does it look like?

- Evidence indicates death by terminal dehydration is not painful (Berry 2009)
- Benefit of dehydration: reduction in UOP, GI secretions, Pulmonary/pharyngeal secretions and edema
- Problematic symptoms: Dry mouth, confusion, potentially DVT/PE due to immobility

- What physiological process occurs when ALL food and fluid is declined?
  - Brain/kidneys detect dehydration as a change in solute concentration and secrete ADH
  - ADH tells kidneys to conserve water and causes mouth to feel thirst. **Mouth gets dry.**
  - When H2O resorbed H+ increases resulting in metabolic acidosis, causing hyperventilation to remove CO2. **Patients breath heavier or irregularly**.
  - Glucose stores are mobilized till exhausted, then protein catabolism ensues releasing ketones
  - Ketosis decreases hunger, decreases pain perception and can induce euphoria
  - Decrease in glucose, electrolytes available for brain activity results in **sedation/coma**
  - Decrease in available energy source, electrolyte abnormalities results in cessation of cardiac contractions and death. **Heart stops**.

VSED: for the caregiver

- VSED does result in need for personal care, medical care and support
- Most medications should be discontinued except those needed for comfort
- May require SL, SQ, TD administration
- Care should be given to not interfere by offering food or fluids except as needed for oral comfort such as ice chips, and small amounts of cold fluid or swabs
- Receptors in mouth tell brain thirst is quenched w/ice chips/small amounts cold fluid
- Excellent oral care with peroxide, artificial saliva rinses and gentle brushing of teeth, gums and tongue, as well as lip moisturizer.
- Assist with normal hygiene (baths/bowel/bladder), as well as positioning
- Calm, quiet, temperate atmosphere with provision of those people, animals or things loved and requested by the patient

VSED: the clinician's role

- We will discuss further any potential obligation to offer VSED
- We have already discussed the Palliative Care clinicians 'step back' and explore what can be behind the request for VSED
- If a clinician has moral distress around VSED, then care should be taken to find and transfer the patient to the care of another suitable clinician without any lapse in appropriate provision of care
- **Once VSED is undertaken, the clinician should:**
  - Continuously educate all re: what to expect
  - Review medications to eliminate those no longer necessary to maintain comfort
  - Plan for potential symptoms and arrange for appropriate interventions to be ready
  - Educate all caregivers and bedside clinicians about the process of VSED
  - Anticipate questions about timing, about pain/symptoms, about starvation
  - Have a plan to address how to handle a patient undertaking VSED who in their delirium requests food/fluid

VSED: the outcome

- Generally death is peaceful and occurs in 1-3 weeks depending on starting body habitus, comorbid conditions, underlying pathology and patient age.
- Occasional delirium/agitation indicates uncontrolled symptoms that should be addressed
  - Pay particular attention to ability to void, urinary retention. Catheter may be required
  - Pay particular attention to defecation as need to evacuate bowels does NOT go away with VSED
  - Electrolyte and glucose abnormalities can cause delirium that will require medication administration/adjustments
  - Other etiologies e.g. CVA, DVT, PE, hypoxia, may occur but goal remains management of any resulting symptoms, so no need for acute evaluation/testing unless patient goals shift

Case 1:

**ALL cases are fictitious conglomerations of patient scenarios gleaned from my HPM experience

- 103yof ALF resident with significant valvular heart disease and resultant CHF who has had incidental finding of lymphadenopathy with concern for undiagnosed malignancy. Patient is not a candidate for valve repair and has declined any work-up or potential treatment for the presumed cancer. Acute CVA 2 years prior resulted in severe vision loss, legally blind and age has resulted in her being profoundly hard of hearing despite hearing aids. She suffers from mild dyspnea, weakness but remains with PPS 50%.
- Her desire is to do nothing to prolong her life and she anxiously waits on death.
- Every visit she asks: “how am I doing?”
- When told she is stable, she refuses to speak any further.
- Asks chaplain: “Why won’t God take me?”
- She can’t hear; she can’t see; she enjoys nothing offered to her and is despondent with the ‘waiting’
- No active evidence of disease progression. Medications are already only symptom meds.
- Nothing to refuse or discontinue.
- **Should she be informed of the option of VSED?**

Should she be informed about VSED as an option?

- Is oral nutrition and hydration a medical intervention?
  - Arguments for/against?
- If FEN is a medical intervention it can therefore be accepted or refused
  - Chief Justice Rehnquist observed: “It seems odd that your bodily integrity is violated by sticking a needle in your arm but not by sticking a spoon in your mouth.”
    - Oral Argument at 13:39 to 13:46, *Vacco v. Quill*, 521 U.S. 793 (1997)
- Should the option of refusing therefore be included in informed consent?
- **An informed consent** can be said to have been given based upon a clear appreciation and understanding of the facts, implications, and consequences of an action. Adequate informed consent is rooted in respecting a person's dignity. To give informed consent, the individual concerned must have adequate reasoning faculties and be in possession of all relevant facts.
- Legal uncertainties revolving around VSED lead some caregivers to undermine a patient’s decision to stop eating and drinking. Either the option is not offered, or, if it is requested, the request is ignored.

Case 2:

**ALL cases are fictitious conglomerations of patient scenarios gleaned from my HPM experience

- 56yof with 3y h/o ovarian cancer with recurrent pelvic disease and diffuse omental disease. No further chemo options as disease has been aggressive and progressed with all previous interventions. Has had 50# weight loss with h/o intractable nausea, emesis which is now fully controlled with ATC IV medications. She is a weak 40%.She is able to take oral food and fluids comfortably. Refusing bowel work and has infrequent, small hard stools which exacerbates her nausea, but no current bowel obstruction concerns.
- She is mortified by the need for assistance with her bowel hygiene.
- She prefers the room to be dark and is short-tempered and frustrated by any nursing or clinician interventions, as she feels totally unable to find rest and peace.
- All medication is now IV and she is declining her trays with minimal fluid intake recorded.
- **Is allowing VSED abuse/neglect?**

Is allowing VSED abuse and neglect?

- Concern emanates from legal precedent in elder care:
  - LTC: Dehydration, malnutrition, and the deprivation of essential services like food and water are key indicators of abuse and neglect.
  - CMS "provide each resident with a nourishing, palatable, well-balanced diet that meets the daily nutritional and special dietary needs of each resident."
- This body of abuse and neglect law is totally distinguishable from VSED on the ground that it is directed at *involuntary,* not voluntary, dehydration and malnutrition.
- The Medicare and Medicaid Conditions of Participation clearly provide that residents have "the right to refuse treatment."
- State law also provides that following a patient's or resident's instructions cannot constitute abuse or neglect.
- While federal and state laws are aimed at protecting vulnerable individuals, these same laws place an even higher priority on honoring patient autonomy.
- The regulations were never meant to override the right to refuse.
- In short, while failing to provide adequate nutrition and hydration can constitute abuse and neglect, it constitutes neither when the patient specifically consented.
- Indeed, providing nutrition and hydration over a patient's objections could constitute abuse.

The doctor cannot owe to the patient any duty to maintain his life where that life can only be sustained by intrusive medical care to which the patient will not consent.

Airedale NHS Trust v. Bland [1993] All E.R. 821, at 882 (Eng.).

Case 3:

**ALL cases are fictitious conglomerations of patient scenarios gleaned from my HPM experience

- 90yof NH resident with moderate baseline dementia, Alzheimer's type. FAST 6c. She develops urosepsis and requires hospitalization. Initially responds, then has an 'event' with resultant somnolence. Fails swallow study and offered PEG which family refuses based on her LW. Son is POA/HCS and LW/DNR is well established some 5y prior to her decline. LW does not allow for HCS to act outside of the directive for no ANH and DNR.
- She returns to NH 5 days later; NPO; PPS 20% and is admitted to hospice, but 24h later, she is alert and sitting up in WC, smiling but non-verbal.
- Staff feel she is hungry as she smiles when asked if she wants something to eat/drink.
- Son refuses to allow staff to even offer food/fluids, or to do a trial of safe oral feeding. He feels her LW was clear re: her desire for nothing life-prolonging, including FEN.
- **Can VSED be non-contemporaneous?**

Ky LW

LIVING WILL DIRECTIVE

If I do not designate a surrogate, the following are my directions to my attending physician. If I have designated a surrogate, my surrogate shall comply with my wishes as indicated below. By checking and initialing the lines below, I specifically:

Life Prolonging Treatment (check and initial only one)

☐ _____ (check box and initial line, if you desire the option below)
Direct that treatment be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical treatment deemed necessary to alleviate pain.

☐ _____ (check box and initial line, if you desire the option below)
DO NOT authorize that life-prolonging treatment be withheld or withdrawn.

Nourishment and/or Fluids (check and initial only one)

Can we honor non-contemporaneous VSED?

- Many patients at the end of life lack the capacity to make their own healthcare decisions.
- Fortunately, because of the value placed on autonomy and self determination, mechanisms have been devised through which an individual's autonomy is protected and promoted.
- Courts and legislatures have recognized the patient's right to refuse through prior instructions or through a substitute decision maker. While they still retain capacity, patients can determine the circumstances under which VSED should (later) be implemented.

AD example language

- If I ever suffer irreversible central nervous system damage to the point that I do not recognize my family, I believe that it would be best for me to die. . . . [D]o not place food or water in my mouth. Instead, place it on my bed table. If I feed myself, I live another day; if I do not, I will die and that is fine.
  - William A. Hensel, *My Living Will*, 275 JAMA 588, 588 (1996)

Summary

- VSED is legal in the United States
- VSED is founded in ethical principals of autonomy
- VSED is a right, founded in the right to refuse
- VSED could be considered a legitimate exit option

- VSED can be important to informed consent
- VSED can be instrumental in alleviating patient distress around control, loss of self
- VSED can cause clinicians moral distress

- VSED is rarely talked about, rarely openly/intentionally utilized

- Personal and organizational support for VSED involves careful consideration, planning and need for clinical guidance/protocols and extensive education.

Questions/comments/suggestions???

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References

- Frontiers in Pharmacology; March 2018;vol 9;article 294
- Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 310 (1990) (Brennan, J.,dissenting)
- T. Pope and L. Anderson, "Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life," *Widener Law Review* 17, no. 2 (2011): 363-427.
- Lachman, V.D.(2015).Voluntary stopping of eating and drinking: An ethical alternative to physician-assisted suicide. *MEDSURG Nursing*, 24(), 56-59.
- Jox et al. *BMC Medicine* (2017) 15:186
- Christenson. JHPN (2019) 21:3
- Thaddeus Mason Pope and Amanda West, "Legal Briefing: Voluntarily Stopping Eating and Drinking," The Journal of Clinical Ethics 25, no. 1 (Spring 2014): 68-80.
- M Rady and J Verheijde, "Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death:, 27Am.J.Hospice & Palliative Med. 205, 206 (2010)
- Linacre Q. August, 2014; 81(3): 279–285. "How should a Catholic hospice respond to patients who choose to VSED in order to hasten death?"