Voluntarily Stopping Eating and Drinking
Ethical Considerations in Organizational Policy Development

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Session goals

1. Define VSED
2. Describe clinical course of VSED
3. Explore ethical questions raised by VSED
4. Propose elements of sound organizational policy
Defining VSED

Section I

1. Voluntary stopping of eating & drinking by adult patients who
   a. have decision-making capacity,
   b. are otherwise able to eat and drink without assistance,
   c. have intolerable suffering arising from a terminal illness;
2. with the explicit intent of relieving that suffering by hastening their own death.

VSED: definition

1. Voluntary stopping of eating & drinking by adult patients who
   a. have decision-making capacity,
   b. are otherwise able to eat and drink without assistance,
   c. have intolerable suffering arising from a terminal illness;
2. with the explicit intent of relieving that suffering by hastening their own death.

(1, 2, 3)
Clinical Course of VSED

Section II

Fasting hospice pts undergo shift from fat to protein metabolism & enter state of ketosis.

Consciousness fades as ketosis advances & may be associated with diminished pain & mild euphoria.

Continued ketosis > organ failure (kidney & liver), uremia, electrolyte imbalance, coma & fatal heart arrhythmias.

Death usually occurs within 10 to 14 days & depends on preexisting condition & disease.

VSED: Clinical Course

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VSED: Symptom Burden

- Within context of good palliative care, experts agree that VSED does not contribute to suffering among terminally ill (4, 5)
- Fasting rarely causes discomfort from hunger
  - usually transient & stops within 24–48 hours
- Fasting is associated with feelings of dry mouth
- Dry oral & pharyngeal mucus membranes readily relieved by simple measures

VSED: Psychosocial Burden

- Because process of dying unfolds over time, the ‘wait’ can be difficult for patients and loved ones
- That the patient has chosen to hasten death can be experienced as abandonment by loved ones
- That the patient has chosen to intentionally hasten death can be morally challenging for care givers who see this as an immoral act of suicide
- Fear that VSED will cause additional pain/suffering
- Fear that VSED is illegal or professionally unsanctioned may add to caregiver distress
Ethical Questions

Section III

Ethical Analysis of VSED

- VSED is self-directed; hospice care provider involvement is limited to three phenomena
  - Disclosure/explanation of option
  - Continued palliation of symptoms, both from underlying disease and from VSED
  - Continued presence/support of patient/family

- In what ways are these phenomena ethically significant for hospice care providers?
Hospice Philosophy of Care

1. Preserving the integrity of persons and supporting the exercise of moral agency
2. The nature and relief of suffering
3. Family-centered care
4. Dying as an experience pregnant with meaning

Integrity and Moral Agency

Support exercise of moral agency by:
- disclosing option of VSED to patients
- explaining to patients/families what experience has been like for other patients who choose option of VSED
- assuring patients/families that hospice care team will continue to support them and provide intensive symptom management if VSED is chosen
Integrity and Moral Agency

- Support patient’s integrity by
  - Acknowledge/respect patient’s considered conclusion that continuing to live with present suffering is an insult to personhood
  - Understand that alternate interventions to restore/reconfigure personhood not acceptable to patient

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Nature and Relief of Suffering

- VSED appears to produce outcome consistent with hospice and patient/family goal of relieving suffering
- In cases where families or clinicians disagree with VSED, watching the patient complete the process can be a source of suffering in families/clinicians

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Family-centered Care

- Educating families about what to expect as VSED progresses, providing support as the patient dies, and providing bereavement support after death are all consistent with the hospice value of family-centered care.
- Honoring a patient’s choice to proceed with VSED risks fracturing relationship between family and clinical team.

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Dying Process Pregnant with Possibilities of Meaning

- Hastening death inconsistent with traditional interpretation of hospice value of finding/creating meaning during all phases of the dying process.
  - Closes off opportunities to find/create meaning until the time of death.
- Relief of suffering via hastening death raises questions of proportionality.
  - Relief of suffering at the expense of shortening dying process.

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Dying Process Pregnant with Possibilities of Meaning

Restoring moral agency and giving patient control over circumstances of death can empower them to find/create meaning more effectively in the time they have remaining.

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Developing Sound Organizational Policy

Section IV
Case Study

Betty’s VSED experience

Why develop policy?

- Patients/families can experience distress if
  - clinicians’ responses to questions are uninformed, inconsistent, or judgmental
- Clinicians can experience distress if
  - they lack resources to respond to patient/family questions
  - there is conceptual confusion about practice
  - they lack clarity about organization’s position on practice
- Patient access to information/support can be uneven across organization
Effective policies

- Stakeholder buy-in
- Accessibility
  - Education
  - Availability
- Clarity & precision
  - Give the guidance needed in the moment
- Regular review
  - Ensure policy is supporting desired process/outcomes

VSED Policy

- Mission and values of organization
- Clearly and succinctly define VSED
- Explain that, how, and in what conditions supporting patient choice to VSED is/is not consistent with organization’s mission and values
- Link to effective procedure

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Iterative Policy Development (8)

1. Review current policy
   • identify strengths
   • identify gaps

2. Identify affected parties and establish task force

3. Conduct literature review

4. Identify conceptual context
   • organizational values
   • legal/regulatory requirements
   • clinical evidence base
   • position statements

5. Consult experts

6. Re-frame issue

7. Formulate policy

8. Draft procedure

9. Solicit feedback
   • Internal stakeholders
   • External experts

10. Develop implementation plan

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Iterative Policy Development

11
Obtain BOD approval

12
Implement

13
Review/revise annually

Conclusions

- Clear & accurate understanding VSED
- Value of organizational policy development
- Consider VSED in context of mission and values
- Iterative policy development process
- Regular review of policy and practice
We Welcome Further Discussion

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References


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