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

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Defining VSED

Section I

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)

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Clinical Course of VSED

Section II

VSED: Clinical Course

- 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

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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

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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

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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?

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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

(6, 7)

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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

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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 Possibilties 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 Possibilties 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

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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

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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

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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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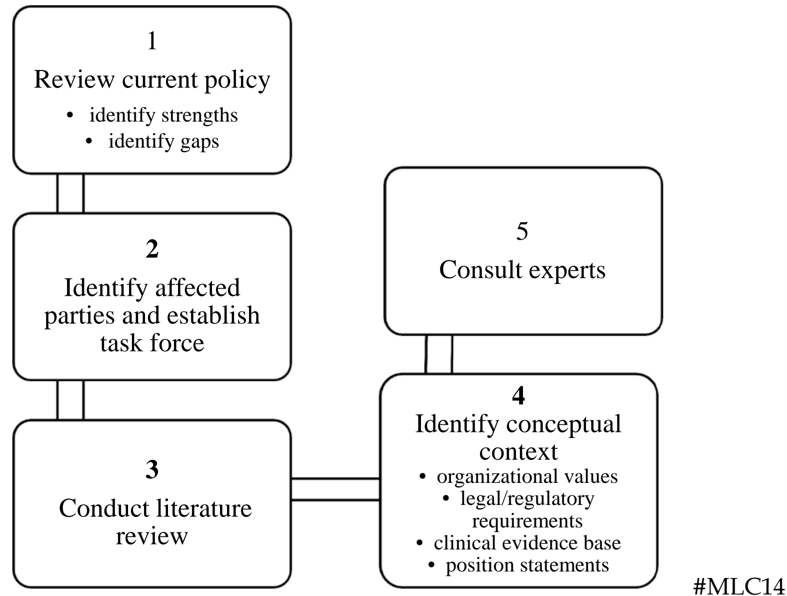
Iterative Policy Development (8)
1
Review current policy
• identify strengths
• identify gaps
2
Identify affected parties and establish task force
3
Conduct literature review
4
Identify conceptual context
• organizational values
• legal/regulatory requirements
• clinical evidence base
• position statements
5
Consult experts
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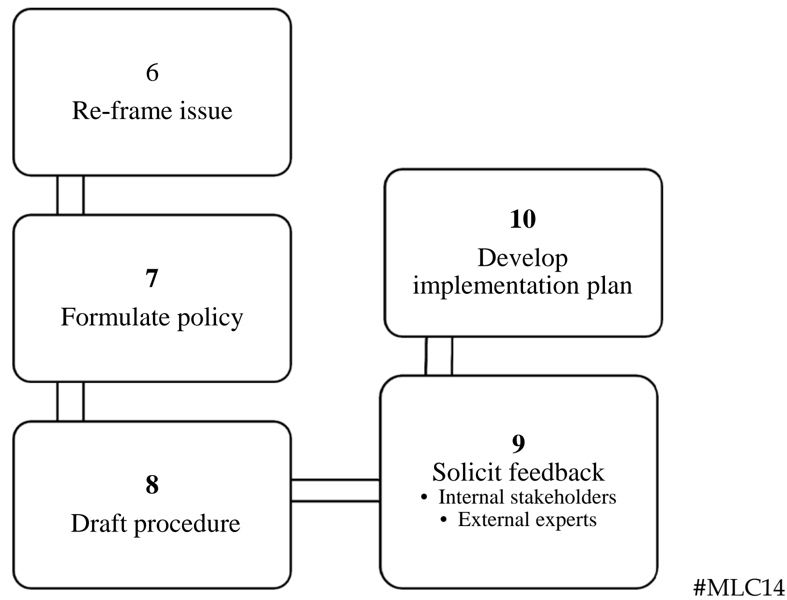
Iterative Policy Development (8)
6
Re-frame issue
7
Formulate policy
8
Draft procedure
9
Solicit feedback
• Internal stakeholders
• External experts
10
Develop implementation plan
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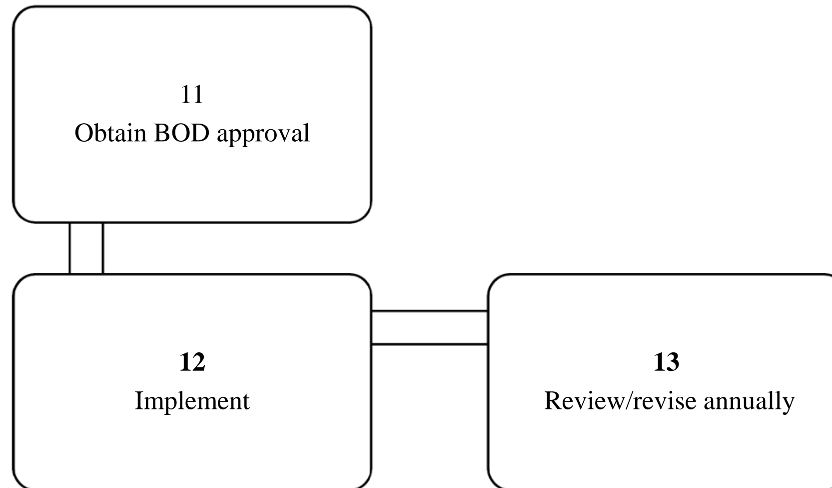
Iterative Policy Development (8)



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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

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We Welcome Further Discussion

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