When hospice patients request support for VSED: Organizational policies that guide clinician responses are a good FIRST step

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Clinical source of VSED cases

- End of Life Choices New York works to improve care and expand choice at the end of life
- Not-for profit organization providing pt support in NYS for more than 12 years
- Support 2 groups decisionally capable, suffering patients: those currently terminally ill & others with incurable & progressive diseases
- Work closely w hospice & palliative care programs
- Some hospices in greater NYC have developed VSED policies

Plan to present & discuss:

1. Voluntarily Stopping Eating & Drinking (VSED)
   - prerequisites for 'successful' outcome
   - definition of 'successful' outcome
2. Key ethical & clinical concerns when patients request VSED information & support
3. Benefits of developing organizational policy re VSED to address those concerns
4. Clinical reality with & without VSED policy

Defining VSED

- *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 an incurable/progressive *or* terminal illness
- Patient initiates fast with explicit intent of relieving that suffering by hastening his/her own death
- Decision is informed, voluntary, enduring & consistent with known preferences/values

Prerequisites for 'successful' outcome

1. Decisionally capable & informed patient with *very* determined will to hasten dying
2. Requires ability to forgo all fluids…death is caused by dehydration [NOT starvation]
3. Care-giving support–often 24/7 as death nears
4. Psychosocial/family support for choice & process
5. Access to hospice or palliative medical over-sight & symptom management

‘Successful’ outcome defined

- Peaceful, gentle death that occurs within days to two weeks of start of fast
- Process of dying not associated with significant pain or great suffering
- Family &/or caregivers support VSED decision & process, & are at peace with the outcome

Physiological course of VSED

- Time to death depends upon underlying disease load & physiological/nutritional status
- Fasting hospice pts undergo shift from glycogen to fat metabolism → ketosis, and eventually protein metabolism
- Advanced ketosis associated with dulling of CNS & sensorium > feeling diminished pain & [occasionally] mild euphoria
- Continued ketosis > organ failure (kidney & liver), uremia, electrolyte imbalance, coma, heart arrhythmia & death within days to 2 wks.

VSED symptom burden

- Within context of good palliative care, clinicians agree that VSED does not contribute to suffering among terminally ill
- Fasting rarely causes discomfort from hunger – usually transient & stops within 24 – 48 hours
- Feelings of dry mouth & thirst can be challenging
- Dry oral & pharyngeal mucus membranes usually relieved by simple measures [good oral care]
- Dying by VSED is a process that unfolds over time requiring pt resolve, determination & patience

Hospice support for VSED choice

- VSED is an exercise in self-determined choice by capacitated adult with legal/moral right to dominion over own body
- Hospice care involvement limited to:

1) Disclosure & explanation of VSED option
2) Continued palliation of symptoms, both from underlying disease and from effects of VSED
3) Continued presence & support of patient & family & bereavement support after death

Why is a VSED policy beneficial?

- VSED is a frequently occurring choice by hospice patients
- Spokesperson for NHPCO recently said:

"The topic of VSED will come up in just about every hospice, so it's important that hospice teams have robust discussions on this issue and are able to respond if the subject does come up from those they are caring for. Hospices should certainly consider developing a policy if they do not have one in place but the topic itself should be one all hospices are familiar with."

Clinicians' concerns, questions, conflicts

- Concern that pt's intention to *hasten* death may conflict w fundamental hospice values
- Concerns that decision to hasten death by VSED morally indistinguishable from suicide
- Fears that providing VSED support may be illegally assisting in suicide
- Worry that VSED choice suggests clinicians have not met all EOL needs >> pt's desire to hasten death

Potential Benefits of Having a VSED Policy

- So clinicians:
  - Have clarity on and understanding of the process
  - Have the resources to respond to pt/family questions
  - Have "stakeholder buy-in"
  - Respond in consistent manner across disciplines
    - Same training
    - Policy may help alleviate bias by discipline

Case History of how one hospice developed a VSED policy

- Retrospective case of pt who had chosen VSED
- Staff conflicted: pt control vs hastening death
- Brought to Ethics Committee
- Used opportunity to float idea of VSED policy
- Asked NHPCO members if they had policies to share
- Simultaneous suicidal ideation policy created

The Policy

- Purpose: To support pt-with-capacity's autonomous right to make decisions about their care.
- Recognizes that VSED is not suicide
- Procedure:
  - Team members speak to pt
  - Decisional capacity assessed
  - Team meets and ascertains whether decision is rational, voluntary
  - Verify that pt's support system is aware of decision and willing to support pt
  - Ascertain whether primary MD will continue to care for pt.

The Policy (cont)

- Explain anticipated physiological process to pt, caregivers, family
- Explain to surrogate/family that pt's decision is binding even when pt loses capacity
- Guarantee staff will provide symptom management and any other necessary support
- Assure pt that they can stop process at any time
- Allow conscientious objection in staff

Comparison with another hospice's VSED policy

Topic	My Hospice	Other Hospice
Discipline meeting with pt	RN/SW	MD
Consent form for VSED	No	Yes
Pt can resume eating/drinking if they request it	At any time	Only if of "sound mind"

Implementation

- Implementation:
  - New policy reviewed with teams

  But ….
  - No training
  - No feedback loop

An "unsuccessful" VSED case

- "Sam" – a married man in mid 80s w inoperable cervical stenosis & insulin-dependent diabetes
- Advancing nerve damage > inability to stand or use hands > became bedbound & unable to participate in activities that previously provided joy
- Despite efforts at palliation by geriatrician, his quality of life so deteriorated he decided to stop all life prolonging measures: insulin & food/fluid
- Referred by geriatrician to home hospice program

Unsuccessful case cont'

- Multiple visits by hospice team during 1st wk of enrollment; team voiced concern re difficulty of fasting
- Team recommended pt slowly stop oral intake, thus pt continued to drink during initial 10 days
- Possible impaired communication between 'replacement' hospice RN during regular RN's vacation
- Only analgesic provided = liquid Tylenol, along w ativan & haldol through end of 2nd wk
- Pt complained of ^ pain, appeared uncomfortable & restless – occasionally agitated; no insulin x 2 wk

Unsuccessful case - concluded

- Wife repeatedly asked for stronger analgesia, specifically morphine – request denied
- On day 18 of pt's fast, wife sent the following email: "A [hospice-provided] *licensed practical nurse stayed with us overnight and obtained the go ahead for morphine and atropine. It was quite clear to her that he was in pain - all the grimacing and moving around. He is now sleeping peacefully.*"
- He died the next morning
- This hospice had a VSED policy

Another case…

- "Sarah" was 103 yrs of age when she 1st contacted EOLCNY…just wanted info re *FUTURE* EOL options
- Lived w wonderful W African aid & had a busy life – she had been in same writing gp > 30 yrs
- Essentially healthy – visual challenges & used cane for steadiness…managed well, often out & about
- Year later she called again
- Acute SOB > own MD > pulmonologist > Xrays > collapsed lung > O2 round clock & home bound

2nd case…concluded

- Immediately got her enrolled in home hospice
- Small doses of MS > palliative relief
- She called son & grandkids together to tell them
- “I’m done”
- After several weeks of goodbyes, she began to fast
- Died very peacefully 4 days later
- This hospice did not have a VSED policy but medical director & team were both sympathetic & experienced in support of VSED cases

What would you do?

- 100 year old woman. Failure To Thrive
- Living with 70 year old, never-married son
- Met with son first. Deeply invested in keeping mother alive
- Pt is alert and oriented x 2-3
- Much to my surprise …… She takes my hand and asks if I can help her die.

Thank You

For your attention

And for your questions

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