Voluntarily Stopping Eating and Drinking

Clinical Aspects

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Disclosure

I have no relevant financial conflicts of interest to disclose.

I have been a long time advocate for expansion of palliative care and hospice and for allowing physician assisted death and other last resort options including VSED for terminally ill, suffering patients.
**Palliative Options of Last Resort: Why are they important?**

Reassurance for witnesses of bad death

Potential escape when suffering unacceptable

Awareness of potential options important to some patients, families, and caregivers

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**PALLIATIVE CARE Correctable Limitations**

Limited access to care

Inadequate physician training

Barriers to pain management

Palliative care offered too late

Physician lack of commitment
PALLIATIVE CARE
Uncorrectable Limitations

False reassurance
Exceptions unacknowledged
Uncontrollable physical symptoms
Psychosocial, existential, spiritual suffering
Dependency, side effects
Devaluation of some patient choices

Limitations of Palliative Care
Prevalence of Symptoms in Dying Patients

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weakness</td>
<td>39-91%</td>
</tr>
<tr>
<td>Pain</td>
<td>49-62%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>8-76%</td>
</tr>
<tr>
<td>Immobility</td>
<td>41%</td>
</tr>
<tr>
<td>Constipation</td>
<td>4-51%</td>
</tr>
<tr>
<td>Urine incontinence</td>
<td>35%</td>
</tr>
<tr>
<td>Cough</td>
<td>6-45%</td>
</tr>
<tr>
<td>Nausea/vomit</td>
<td>9-44%</td>
</tr>
<tr>
<td>Dysphagia</td>
<td>4-25%</td>
</tr>
<tr>
<td>Confusion</td>
<td>9-24%</td>
</tr>
<tr>
<td>Pressure sores</td>
<td>14%</td>
</tr>
<tr>
<td>Fecal incontinence</td>
<td>13%</td>
</tr>
<tr>
<td>Odors</td>
<td>5%</td>
</tr>
</tbody>
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Two Aspects of the Clinical Question

What options do I have...

...if my dying becomes unacceptably difficult in the future?

...NOW because my dying is unacceptably difficult in the present

Reassurance about the future

Commitment to be guide and partner

Explore hopes and fears
  • What are you most afraid of?
  • What might death look like?

Commitment to face worst case scenario

Freedom to worry about other matters
Will you help me die – now?

Full exploration; Why now?
- What makes it most unacceptable?
- What has been tried so far?

Potential meaning of the request
- Uncontrolled symptoms
- Psychosocial problem
- Spiritual crisis
- Depression, anxiety

Potential uncontrolled, intolerable suffering
- Predominantly physical
- Predominantly psychosocial

Will you help me die - now?

Insure palliative care alternatives fully considered

Search for the least harmful alternative

Respect for the values of major participants

Patient informed consent

Full participation of immediate family
Potential Last Resort Options

Accelerating opioids to sedation for pain
Stopping life-sustaining therapy

Voluntarily stopping eating and drinking
Palliative sedation, potentially to unconsciousness

Physician-assisted death
Voluntary active euthanasia

VOLUNTARILY STOPPING EATING AND DRINKING
Main Elements

Result of active patient decision
Patient physically capable of eating and drinking
Requires considerable patient resolve
Takes one to two weeks
Theoretically does not require physician assistance
But physician involvement very important
  • Ensure adequacy of palliative care
  • Capacity assessment
  • Symptom management as process unfolds
VOLUNTARILY STOPPING EATING AND DRINKING
Some clinical challenges

Who should be told about this option in advance?
- All seriously ill patients so they know what is possible
- Only those who ask about assisted dying
- Only those who are dying badly despite good care
- Might a clinician telling unasked about this option seem coercive?

Who might be the best candidates for this option?
- Very disciplined control-oriented patients
- Without a high acute symptom burden (too slow)
- Ready for death that is coming "too slowly"
- Supportive family who agree with the decision

Not eating is relatively easy to manage
- Ketosis sets in relatively early

Not drinking is very difficult
- Drinking small amounts for comfort makes process last too long
- Thirst and mouth dryness get worse over time
- Requires tremendous discipline

Delirium usually sets toward the end from dehydration
- Associated confusion may require treatment
- May lose focus/discipline and want to drink
- May be distressing for patient and family
- May require light or heavy sedation proportionate to level of distress
VOLUNTARILY STOPPING EATING AND DRINKING
Some potential clinical pluses

Definable beginning, middle and end
• Work on "life closure" issues if desired
• Potential for meaningful goodbye
• Possible to change one’s mind in the early going

Does not require direct medical intervention
• Clinicians should be involved in initial evaluation
• Prepared to treat secondary clinical problems (delirium, dry mouth)
• Clinician assistance in death very indirect

VOLUNTARILY STOPPING EATING AND DRINKING
Some potential clinical negatives

No requirement of a terminal illness
• Prognostic criteria not agreed upon
• Potentially available to those with psychiatric illness

Does not necessarily require clinician involvement
• Evaluation is critical (why now?)
• May be a mix of medical and psychiatric motivators

Some clinicians would refuse involvement
• Potential to view as assisting in suicide
• Other caregivers (family or professional) might undermine
Future possibility or current request?

Many patients might be reassured by the **future possibility**
- Especially if they live in states where PAD is illegal
- Gives a sense of control and possibility

A relatively small number will eventually want to activate **now**
- Why now?
  - Careful evaluation for unrecognized/untreated suffering
  - Second opinion from a specialist in palliative care or hospice

PALLIATIVE OPTIONS OF LAST RESORT
Categories of Safeguards

- Palliative care available and insufficient
- Rigorous informed consent
- Diagnostic and prognostic clarity about terminal illness
- Independent second opinion
- Documentation and review
Four Patients – Patient 1

65 year man with metastatic breast cancer
- Refractory to treatment and on hospice
- Mainly bone disease
- Wanted the option of a physician assisted death in the future
- Thought it ridiculous and immature that this option was unavailable
- Discussed the options of sedation or VSED if needed in future
- Quality of life acceptable for 12 months

Suddenly developed multiple pathological fractures in legs
- Could not walk or get out of bed without severe pain
- Pain easy to control when not moving at all
- Ready to die now and wanted PAD, but in hospital and in New York
- Accepted the option of VSED, and diligently did not eat or drink
- Died peacefully and comfortably 10 days later

Patient 2

52 year old man with ALS like syndrome as a late complication of radiation for brain cancer
- Had been cured from brain cancer 25 years earlier
- Fiercely independent motorcycle rider
- Progressive neuromuscular weakness over the past 5 years
- Bedbound over the last year; dependent on aides for ADL’s
- On hospice at home; wanted the option of PAD
  - Prognosis might not have qualified even in legal states
- No pain, but eating and drinking was an ordeal
- Presented an alternative “option” of VSED
- Felt less trapped knowing he had a potential escape

Eventually decided he was “ready” about 6 months later
- Second palliative care opinion and an ethics consult
- Home health aides refused to participate
- Admitted to our acute palliative care unit; died 2 weeks later
Patient 3 - A More Challenging Case

60 year old woman with advanced colon cancer
- Fighting her disease for over 4 years
- No more effective treatments available
- Very debilitated and weak
- On home hospice but dying was taking too long
- Wanted to know options in NY for a hastened death
- Explored VSED with her and family

Several weeks later initiated the process
- Found not drinking very difficult
- Kept taking sips and resumed eating several times
- Patient, family and staff on an emotional rollercoaster
- Eventually died several months later
- Family and staff felt as if they had failed at several levels

Patient 4 - An Even Challenging Case

48 year old nurse with severe intractable depression
- Frequently hospitalized with suicidal ideation
- Tried psychotropic medications in multiple combinations over 10 years
- Multiple courses of ECT
- Institutionalized for 3 months
- Spoke compellingly about his unrelieved suffering and need for escape

Severe depression
- Unrelenting suffering despite multiple treatments and therapists
- Seemingly intractable but not ‘terminal’ illness
- Challenge that suicidal ideation part of his illness
- Significant risk that he would die from a violent suicide
- I did not tell him about VSED nor offer him any last resort options
- Still alive many years later...
Potential Clinical Benefits of Being Explicit about Last Resort Options like VSED

- Reassure patients that they could escape their biggest fear
- Most would not act even if available
- Potentially frees energy to spend on other matters
- Redouble our commitment to be responsive to patient suffering
- Potentially allows an escape if dying becomes too prolonged
- Escape is primarily under the patient’s control

Potential Clinical Risks of Being Explicit about Last Resort Options like VSED

- Might frighten some patients
- Might lead to pressure to prematurely choose death
- Could undermine progress in hospice and palliative care
  - Lessen commitment to address difficult suffering
  - Providing an “easy out” as suffering increases
- Might undermine fundamental clinician/societal values
Voluntarily Stopping Eating and Drinking
The Bottom Line Clinically

Only sensible in context of excellent palliative care
Many patients unaware of this option – selectively informed
Patients must be competent, strong willed, and not suffering acutely
Currently, VSED unevenly / unpredictably available
Some patients, family members, clinicians, others cannot support
Should be subject to similar safeguards as other last resort options
Can help support personhood in difficult cases

VSED and other Last Resort Options:
The Bottom Line Clinically

Clarity about which last resort options are available, and under what circumstances, is beneficial
• Reassure those who fear a bad death
• Increase responsiveness to extreme suffering
• More ability to address unique circumstances
• More accountability when suffering persists
Some Clinical References


