VSED: DEMENTIA, DEPRESSION, AND CAPACITY DETERMINATIONS

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Outline

- Determining decision making capacity (DMC)
- Mental disorders that may impact VSED
  - Depression
  - Dementia
  - Delirium
**Hard Cases**

- Easy Cases - patient with terminal illness, already hospice enrolled, diminished appetite and thirst, decides to stop eating and drinking fluids, family supportive and prepared for death, patient remains comfortable until death.
- Positive views on VSED from hospices professionals may reflect reporting bias.
- Hard cases—examples
  - Patient who decides to pursue VSED before losing autonomy to progressive neurological disease, otherwise only mild to moderate illness burden and suffering, not yet hospice enrolled. Develop delirium and thirst during VSED and requests water.
  - Patient who decides to pursue VSED, has advanced physical illness, but also mental disorder with difficult to determine effect on capacity.
- This talk will focus on hard cases.

**Elinor**

- 92 years old, hearing impaired, early dementia, urinary incontinence, but otherwise healthy, partially dependent in instrumental activities of daily living.
- Lives in small Oregon town, all grown children there.
- Unable to hear family conversations, had to give up bridge and golf.
- Two years of consistently saying she was “done”. Bitter not eligible for Oregon Death with Dignity Act. Not depressed, just tired and played out. Tried one week of antidepressants and one week of medications for urinary incontinence. Adverse effects intolerable. Disliked hearing aids, unable to adapt to them.
- Talked about VSED for one year before started.
Elinor

- Set a date for 2017, then started to move up date, with goal to see great grandchild one more time
- Elinor was highly private and wanted to embark on VSED with only daughter’s help. She did not want hospice involved.
- Long time physician had recently retired, she declined to see new physician, but secondary to extensive community connections, a physician agreed to come to her home and evaluate capacity for VSED.
- Hospice notified. Wanted to help, but little experience. Could not enroll her until after VSED started

Elinor

- Day 1--2 of VSED went well.
- Day 3—Developed mild delirium with agitation. Started low dose lorazepam—paradoxical activation.
- Day 4--Hospice arrived, nurse unfamiliar with VSED, biased toward non medication approaches.
- Day 4-5—Delirium worsened. Elinor forgot what was going on intermittently, had worsening emotional lability, needed constant distraction from thirst, had falls despite two people with her at all time.
- Day 5--family called hospice in evening stating she was suffering and situation was not tolerable. Haloperidol and morphine started quickly.
- Peaceful within hours, died 36 hours later
- Six months later, family feels good at honoring her wishes and overall quality of death
- Biggest challenge in retrospect: “logistics”
George

- 83 year old Veteran with advanced Parkinson’s disease
- World War 2 in Pacific theater—carried a bullet in case of capture
- Married over 50 years to wife.
- She reported many year history of worry about loss of control at end of life. Had cut out many newspaper articles over the years about VSED and suicide at the end of life.
- Started VSED at home, became confused, requested food.
- Wife told she could be arrested for abuse if she did not feed him.

George

- Admitted to VA nursing home
- Seen by geriatric psychologist—had decision making capacity, not depressed.
- Signed advance directive instructing that he not be given food or fluids once he started VSED.
- Started VSED twice, each time became delirious, requested water and food, nurses gave him oral fluids/pudding
- Each time, after being given fluids, his delirium resolved, he fell asleep, when awoke he was furious he had been give fluids
- Significant conflict among nursing on whether his advance directive should be honored
- Third time he was given substantial sedative medications early in the course of delirium for thirst, died comfortably
Esther

- 82 year old
- 33 psych admissions over 17 years for psychotic depression
- Typically presented over a few days with psychomotor retardation, suspiciousness, stopping all oral intake, muteness
- Responded to ECT and support
- Developed comorbid dementia, thought to be Alzheimers disease
- Good family support, active durable power of attorney for health care
- Stopped responding to usual psychiatric treatments
- Enrolled in hospice, continued psychiatric medications, allowed to stop eating and drinking, died peacefully

WHAT IS DECISION-MAKING CAPACITY (DMC)?

- “The ability to understand the basic information necessary for informed consent and understanding the nature and consequences of authorizing treatment.” (Oregon Health Law Manual)

- Appelbaum and Grisso - Four abilities (standards) relevant to DMC:
  - Express a stable choice
  - Understand the relevant information
  - Appreciate the information
  - Use reason and logic in making the choice
CAPACITY IS NOT “ALL OR NOTHING”

- Focused assessment
- Can have capacity in one area, but not another
- Medical DMC is limited to particular medical decision
- DMC needed for informed consent/refusal
- Concept of sliding scale—as the risks of refusal of care increase, clinicians can appropriately use more standards and higher thresholds for determination of DMC.
  - Which thresholds and standards for VSED depend on the situation.

More On DMC

- DMC impairments often transient
- When assessing DMC, more weight should be given to the process the patient uses in coming to their decision, than whether the clinician agrees with the decision.
- No simple tools or standards that can be used to determine DMC.
- Even expert assessment results in uncertainty at times.
- Finding of lack of capacity doesn’t mean treatment is feasible or reasonable.
WHY DO PATIENTS LACK CAPACITY

- Psychiatric disorders that impair DMC
  - Dementia
  - Delirium
  - Schizophrenia
  - Depression
  - Mania
- Executive/frontal impairment may tie these together
  - Use efficient problem solving
  - Use past experiences to anticipate future problems
  - Abstraction
  - Give reasons for actions
- Language, culture and education may impact DMC

PAD versus VSED

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<thead>
<tr>
<th></th>
<th>PAD</th>
<th>VSED</th>
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<tbody>
<tr>
<td>Health Care Professional participation</td>
<td>Required</td>
<td>Not required (though difficult to avoid)</td>
</tr>
<tr>
<td>Informed Consent</td>
<td>Required</td>
<td>Not required, if no health care professional participation</td>
</tr>
<tr>
<td>Decision making capacity standards</td>
<td>Clearly delineated in law</td>
<td>Dependent on clinical situation</td>
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<tr>
<td>Physician choice to participate</td>
<td>Physician can choose not to participate</td>
<td>Greater risk of abandonment if patient goes ahead despite physician not wanting to participate</td>
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Physician assisted death (PAD)

- DMC for PAD under Oregon Death with Dignity Act
- Patient must understand that
  - have underlying terminal illness
  - possibility of error in survival estimates
  - lethal medication may cause death, may fail to cause death immediately or in some cases may fail entirely (6/1000 cases in Oregon)
  - ingestion may cause vomiting
  - option of alternatives of comfort/hospice care, terminal sedation etc.
- Decision voluntary without coercion or even undue influence.
- Death with Dignity Laws include added standard—If a mental disorder, particularly depression, is influencing the judgment of the patient around the decision, the patient is disqualified
- Mental health professionals who oppose PAD, also support higher standards (Ganzini et al 1996, 2000)

VSED and informed consent

- Informed consent for VSED more complex
- Lack of information on outcomes needed for complete informed consent
- More adverse trajectories, less confidence on estimates of survival once initiated, more underlying nonterminal conditions, greater dependence on others during the process
- Likely less risk of coercion and undue influence starting process, more risk during process
PAD—additional conditions added by Oregon physicians

- In Oregon physicians often add their own personal and idiosyncratic conditions to determine whether they will participate
  - Authenticity
  - Previous adherence with curative efforts
  - Understandable reasons
  - Reasons that the physician agrees with
  - Patient is likeable/admirable
  - Suffering
- Physicians and other health care professional may add additional conditions to VSED

Dementia

- Dementia is global cognitive decline that affects daily functioning.
- Mild cognitive impairment (MCI) precedes diagnosis of dementia, particularly Alzheimer’s disease (AD).
  - MCI prevalence in persons over age 65 years is 18%.
- Amnestic MCI converts to dementia, mostly AD, at a rate of 10%-15% per year, or 50% over five years.
- Memory impairment and accompanied impairments in:
  - Executive function
  - Personality
  - Visuospatial abilities
  - Language
- Other common dementias:
  - Parkinson’s disease/Lewy Body
  - Vascular dementia
  - Frontotemporal dementia

Lopez, 2003; Rosenberg et al., 2006
Dementia Demographics

- Prevalence of dementia
  - 5.3 million in US have AD
  - Approximately 1/3 of persons over age 85 years have dementia
  - 1/3 of elderly who die have dementia

- Caregivers for persons with dementia
  - 15.4 million caregivers
  - Provided 17.5 billion hours of unpaid care in 2012

http://www.alz.org/alzheimers_disease_facts_and_figures.asp; (Marson, 2013)
Changes in Numbers of Deaths Between 2000-2010 in US
http://www.alz.org/alzheimers_disease_facts_and_figures.asp

Dementia and VSED—Ethical Complexity

- Impacts on will and volition—
  - early dementia
    - apathy and lack resolve
  - moderate to severe dementia
    - lack determination and resolve for VSED
    - Lack ability to remember the desired course.
Dementia and VSED-Ethical Complexity

- Only patients at the early course of a dementing illness have enough cognition to make a competent decision for VSED—as such some will embark on it preemptively.
- Patients with early dementia, at the time they choose VSED, may not have significant suffering, but are anticipating future suffering and the loss of ability to pursue VSED.
- Patients with some non terminal conditions may refuse efforts that are palliative or focused on improving quality of life.
- Higher risk of errors in diagnosis of early dementia.
- High levels of expert disagreement about medical decision making in patients with mild Alzheimers (Marson et al., JAGS, 45:453-457, 1997).

Clinical Features of Delirium

**Prodrome** Restlessness, anxiety, sleep disturbance, irritability
- Attention decreased (easily distractible)
- Altered arousal and psychomotor abnormality
- Sleep-wake disturbance (usually worsens at night)
- Impaired memory (can’t register new information)
- Disorganized thinking and speech
- Disorientation—time, place, person (very rare)
- Perceptions altered—misperceptions, illusions, delusions (poorly formed), hallucinations
- Emotional lability
Delirium is Very Distressing for Patients and Caregivers

- 154 patients with cancer and delirium
- 53% recalled delirium
- Mean delirium-related distress on 0-4 scale, was 3.2 for patients, 3.75 for spouses and caregivers
- Delusions were the most predictive of distress
- No difference in distress between hypoactive and hyperactive delirium

Breitbart, et al Psychosomatics, 2002

Delirium in the Course of VSED

- VSED patients develop dehydration and organ failure which results in delirium
- Delirium very common at end of life—95% of cancer patients develop delirium before death
- Delirium complicates VSED
  - Patients forget why they are not drinking
  - Resolve is undermined, as patient cannot distract self
  - DMC lost
  - Patient may attempt to enforce Ulysses contract
- Ethically and emotionally difficult for caregivers
- Even small amounts of water may prolong the VSED process
- Caregivers need to be prepared to give good mouth care, distract the patient, give sedating and psychoactive medications—can be labor intensive
Depression—Major Depressive Disorder

- Sad, blue, depressed most of the day for at least two weeks
  - Severe enough to impact function and daily living
- Associated with hopelessness, suicidal ideation, weight loss with lack of interest in food, and refusal of care
- Patients who are primarily motivated to VSED by depression, should be treated for depression, not give VSED
- Clinicians may be limited in preventing VSED
  - Guardianship
  - Involuntary commitment
- More complex if depression complicates other advanced or terminal illnesses.

The Effect of Depression Treatment on Elderly Patients’ Preferences for Life-Sustaining Medical Therapy

Linda Ganzini, M.D., Melinda A. Lee, M.D., Ronald T. Heintz, M.D., Joseph D. Bloom, M.D., and Darien S. Fenn, Ph.D.

Summary

- Standards for decision making capacity for VSED are evolving but are likely context dependent.
- Requests for VSED for patients with early dementia or whose illnesses are complicated by depression are ethically complex.
- Delirium that develops in course of VSED may undermine capacity and resolve.
- Patients and caregivers need to be prepared that VSED can be labor intensive and can be difficult to achieve without medical assistance.