Dementia, Withholding Food & Water, and Overcoming Barriers to VSED by Advance Directive

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I have no conflict of interest to report.

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Objectives

Describe VSED.

Identify the limitations of traditional advance directives for dementia.

Describe how patients can authorize VSED when they reach advanced dementia.

Assess the most effective advance care planning for dementia.

Time
May a Michigander leave instructions, “dehydrate me to death” when I reach advanced dementia?

Introduction

More & more jurisdictions expanding EOL liberty

May / must clinicians honor such instructions?
Medical aid in dying

Adults > 18 years old

Decisional capacity

Terminally ill 6-mo prognosis

What

Ask & receive prescription drug
Self-administer

To hasten death

MAID legal in 8 US states

Maybe soon

MAID illegal in 48 including MI

Focus on

SO

Other exit options
Dementia challenge raised repeatedly.

Challenge even in these states:

Cannot satisfy 2 conditions at the same time.

Eligibility requirements in all MAID states:

1
Terminal illness

“incurable and irreversible . . . condition . . . death within six months.”

2

Capacity

“solely and directly by the individual . . . not . . . advance directive”

BUT
Capacity → not terminal

Terminal → no capacity

May change someday

Arbitrary discrimination
But today

No "advance" MAID in the Americas

No help for dementia even here

Women 45+
26% lifetime risk
SO

Other exit options

VSED

Voluntarily Stopping Eating & Drinking

MAID gets massive attention

neglected in academic & policy circles
Define VSED

Physiologically able to take food & fluid by mouth

Voluntary, deliberate decision to stop

**Intent:** death from dehydration

>50% at 8d

>80% at 14d
Bad rap

“Must legalize MAID . . . or else . . . VSED”

Actually

Peaceful

Comfortable

1
1st person narratives

Films - Dying Wish

Phyllis Schacter

TED talks

Narrative Inquiry in Bioethics

A JOURNAL OF QUALITATIVE RESEARCH

FEATURED:

Schacter Phyllis

Phyllis Schacter

Books

Academic journals

TED talks

Schacter Phyllis

Academic journals

Schacter Phyllis

Schacter Phyllis

Schacter Phyllis
>100 Oregon nurses cared for VSED patients

Most deaths:

“peaceful, with little suffering”

“opportunity for reflection, family interaction, and mourning”
Not for everyone

Preferred by many

Even though MAID available, “almost twice” chose VSED

Clinical guidance
Good option

Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness—Clinical, Ethical, and Legal Aspects
Timothy E. Quill, MD; Linda Garfinkel, MD, MPH; Robert D. Truog, MD; Theodore Mason Pope, JD, PhD
JAMA Internal Medicine January 2018 Volume 178, Number 1

CPGs

Caring for people who consciously choose not to eat and drink so as to hasten the end of life

KMG: Royal Dutch Medical Association and VNVN Dutch Nurses’ Association Guide
Growing professional society endorsements

POSITION STATEMENT

Nutrition and Hydration at the End of Life

Effective Date: 2017
Status: Revised Position Statement
Written by: ANA Center for Ethics and Human Rights
Adopted by: ANA Board of Directors

Austrian Palliative Society (OPG)

Freiwilliger Verzicht auf Nahrung und Flüssigkeit um das Sterben zu beschleunigen
Eine Stellungnahme der österreichischen Palliativgesellschaft (OPG)
Recap

Evidence based EOL exit option

Legal concerns

Clinician involvement very important

BUT

Uncertainty, reluctance
Prevalence of Formal Accusations of Murder and Euthanasia against Physicians

<table>
<thead>
<tr>
<th>Action that might be misperceived</th>
<th>Mean rating of risk</th>
<th>SD</th>
<th>Actual number of physicians who were accused based on this action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sedation (the application of pharmacotherapy to induce a state of decreased or absent awareness [unconsciousness] in order to reduce the burden of otherwise intractable suffering)</td>
<td>4.4</td>
<td>1.1</td>
<td>2</td>
</tr>
<tr>
<td>Stopping artificially delivered nutrition/ hydration</td>
<td>3.6</td>
<td>1.1</td>
<td>0</td>
</tr>
<tr>
<td>Stopping enteral nutrition/ hydration in a patient who can eat/drink when requested by the patient</td>
<td>3.3</td>
<td>1.2</td>
<td>0</td>
</tr>
<tr>
<td>Use of palliative and sedative medications in the process of discontinuing mechanical ventilation</td>
<td>3.2</td>
<td>1.3</td>
<td>6</td>
</tr>
<tr>
<td>Stopping dialysis</td>
<td>3.1</td>
<td>1.2</td>
<td>0</td>
</tr>
<tr>
<td>Use of barbiturates for symptom treatment</td>
<td>2.9</td>
<td>1.1</td>
<td>2</td>
</tr>
<tr>
<td>Use of opioids for symptom treatment</td>
<td>2.8</td>
<td>1.2</td>
<td>1</td>
</tr>
<tr>
<td>Use of benzodiazepines for symptom treatment</td>
<td>2.3</td>
<td>1.0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>N/A</td>
<td>N/A</td>
<td>6</td>
</tr>
</tbody>
</table>

Providers ask:

Is VSED legal?

Is VSED illegal?

> 600 palliative care physicians perception of legal risk
Wrong questions

Risk assessment

Law is rarely binary

Measure Mitigate

VSED Legality

Prohibited

Unsure

Permitted
Almost never: express prohibition

No U.S. jurisdiction expressly prohibits VSED

**BUT**

Absence of a red light **not** good enough

Clinicians want *express* permission

No *statutory* permission

**No judicial precedent**
Almost no judicial precedent

No red lights
No green lights

Lack of clarity & guidance

neglected in academic & policy circles
VSED now, patient with capacity

Advance directive for VSED later (when Pt lacks capacity)

VSED now, by patient with capacity

2 case types

1
Why do it

Cancer ALS

Dementia
Progressive illness

Benefits
Burdens

Future Benefits
Future Burdens

Cognitive function

Years
What’s that line?

Different for each of us

When I see people in my close family or see my best friends, I do not know who they are. [3.1]

(This patient is both incontinent and dependent on others to change his diapers.)

I do not use bathrooms. I let my clothes get wet and dirty. Others must change my diapers (nappies). [4.5]
Patient lacks capacity at this time

Patient finds intolerable

Hasten death before losing capacity

Life not intolerable

But act now, because still have capacity

BUT
Too soon

Hasten death while life still worthwhile

Premature dying

VSED

Legality

3

Criminal sanctions
Civil liability
Licensing discipline
Extremely low risk

4 Arguments

1. Right to refuse medical measures

Well established > 4 decades

Right to refuse treatment

Vent
Dialysis
CPR
Antibiotics
Feed tube
Vent
Dialysis
CPR
Antibiotics
Feed tube

Unclear

Vent
Dialysis
CPR
Antibiotics
Feed tube

Not DIY

Cinderella pic
again

Vent
Dialysis
CPR
Antibiotics
Feed tube

ICD
Part of a broader **treatment** plan

Supervised by licensed healthcare professionals

**PAVSED**

Palliated & Assisted Voluntarily Stopping Eating and Drinking

Harvard CEC

**PAVSED**

Highlights *medical role* in palliating symptoms

Highlights the *direct care staff* role in providing assistance

**Recognized** as healthcare by medical profession

**More** position statements (e.g. ANA, IAHPC)
More clinical practice guidelines

ONH = “treatment”

BUT

Right to refuse treatment

Barely established ANH = medical treatment
Medical b/c not “typical human”

Implies ONH is not medical

ONH ≠ “treatment”

Right to refuse medical

That’s okay
2 Right to refuse unwanted measures

Does not matter whether food & fluid is “medical treatment”

Right to refuse any intervention (medical or not)

Right to refuse unwanted contact

Even if it would be clinically beneficial

Battery
Mohr v. Williams (Minn. 1905)

Force feeding is a battery

‘bodily integrity is violated . . . by sticking a spoon in your mouth . . . sticking a needle in your arm’

Move from legal bases, grounds for right
Respond to 2 main legal concerns

3 VSED is not assisted suicide

56 US jurisdictions

“Every person . . . aids, or advises, or encourages another to commit suicide, is guilty of a felony.”

Mich. Penal Code 750.329a

Clinicians worry participation with VSED = assisting suicide

BUT
VSED ≠ AS

AS statutes target **active** conduct

Normally:

“Providing the **physical means** by which the other person commits . . . suicide”

VSED entails only **passive** conduct
No “active” introduction of any lethal agent

Exception

Even if otherwise within scope

“Nothing . . . prohibit or preclude . . . prescribing . . . administering, . . . purpose of diminishing . . . pain or discomfort”

Everything clinician does in VSED expressly exempted from AS statute

Many physicians & hospices support VSED
Alleged risk

"The facility must provide each resident with sufficient fluid intake to maintain proper hydration and health."

42 C.F.R. 483.25(j)
Tag F0327

BUT

0 cases

4 VSED is not abuse / neglect
Recap

Risk = 0
Risk $\sim 0$

VSED now, patient with capacity

Advance directive for VSED later
(when Pt lacks capacity)

Why do it
Contemporaneous VSED

What is “advance VSED”
Complete AD, today

2

Direct VSED in future

3

When reach point that you define as intolerable

4
You lack capacity at that time. That is "advance VSED"?

Viable option?

Can you leave VSED instructions in an AD?

Glendower: “I can call spirits from the vasty deep.”
**VSED Legality**

You can write anything you want in an AD.

But . . . will it be honored?

<table>
<thead>
<tr>
<th>Prohibited</th>
<th>Unsure</th>
<th>Permitted</th>
</tr>
</thead>
</table>

No specific permission for VSED.
Sometimes, advance VSED is prohibited

Wis. Stat. 155.20
“A health care agent may not consent to the withholding or withdrawal of orally ingested nutrition or hydration . . .”

Uncommon but not surprising

Autonomy
Autonomy

Prospective autonomy

No green (yet)
Some red

Patient Advocate

Broad powers
Patient can

Advocate can

Mich. Comp. L. Ann. § 700.5509
“A patient advocate . . . exercise powers concerning . . . care, custody, and medical . . . treatment . . .”

Unlike a Wisconsin agent, a Michigan patient advocate may consent to withholding oral nutrition or hydration

BUT

2 conditions
Patient permission

VSED not within default scope of patient advocate authority

Mich. Comp. L. Ann. § 700.5509

“A patient advocate may make a decision to withhold or withdraw treatment that would allow a patient to die only if the patient has expressed in a clear and convincing manner that the patient advocate is authorized to make such a decision . . . .”

2 recent cases

Case 1
DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES",

B. NO NOURISHMENT OR LIQUIDS.

Facility refuses to honor
Family loses

DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES".

B. NO NOURISHMENT OR LIQUIDS.

If you mean hand feeding, say “hand feeding”

Take home lesson

Probably meant this
Case 2

Take home lesson

If you mean hand feeding, say “hand feeding”
Would better ADs have helped MB or NH?

Evidence

Unusual

Practical tips

Be very specific on the when

Be very specific on the what
Tool 1

STANLEY A. TERNMAN, Ph.D., M.D.

My Way Cards® for Natural Dying™

Sort them now to obtain your personal NATURAL Dying—Living Will ... to let others know EXACTLY what you will want, if the time comes when you are too sick to speak for yourself.

© 1999-2013 Stanley A. Terman, Ph.D., M.D.

(Loss of personal identity.)

I do not seem to know it is me when I look in the mirror. I cannot tell others anything about me. [1.1]

When I see people in my close family or see my best friends, I do not know who they are. [3.1]

(This patient is both incontinent and dependent on others to change his diapers.)

I do not use bathrooms. I let my clothes get wet and dirty. Others must change my diapers (nappies). [4.5]
(Leaving bad memories of yourself.)

The way I act now is hurtful or shameful.
I may yell insulting words or take off my clothes in front of strangers. [4.6]

I cannot remember the important events of my life.
If reminded, I don’t know why they are important. [1.2]

I have severe pain. But I cannot say what bothers me.

Doctors don’t see my pain. They do not treat my pain. [2.6]

Tool 2

End of Life Choices

MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING
Advance Directive for Receiving Oral Food and Fluids in Dementia

Clear definitions & prompts

Condition 2

2 conditions

Patient permission
No veto

“Irrespective of a previously expressed . . . desire, a current desire by a patient to have provided, and not withheld . . . life-extending care, custody, or . . . treatment is binding on the patient advocate . . .”

Incapacitated vetoes count

“regardless of the then ability or inability of the patient to participate in care, custody, or medical treatment decisions or the patient's competency.”

Tricky

Case 1
Assume AD clear & valid

Swallowing = revocation

Practical tips

Ulysses contract language
“If I am suffering from advanced dementia . . . my instructions are that I do NOT want to be fed by hand . . . .”

No hand feeding even if “appear to cooperate in being fed by opening my mouth”

Listen to my prior self not my current self

BUT
“current desire”

VSED is important EOL option

Need more education & planning tools

Conclusion
References

Materials from the cases discussed in this presentation are available at http://thaddeuspope.com/braindeath

Medical Futility Blog

Since 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com. This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received nearly 3 million direct visits. Plus, it is redistributed through WestlawNext, Bioethics.net, and others.

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