Responding to Requests for Medical Aid in Dying: Stories from Oregon, Vermont & New York

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Responding to Requests for Medical Aid in Dying:

Stories from Vermont, Oregon and New York

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Potential conflicts of interest

I have no financial conflicts of interest around this topic to disclose.

I have been an advocate for legal access to medical aid in dying as a last resort option in the United States for over 30 years.
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
Conceptual Shift for Palliative Care

Disease-Directed Therapies

Diagnosis    Palliative Care    Death and Bereavement
PALLIATIVE CARE and HOSPICE Correctable Limitations

- Limited access to care
- Inadequate physician training
- Barriers to pain management
- Reimbursement disincentives
- Palliative care offered too late
- Physician lack of commitment
PALLIATIVE CARE and HOSPICE
Uncorrectable Limitations

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

● How to improve access to and delivery of palliative care and hospice services to all seriously ill and dying patients?

● How to respond to those infrequent, but troubling patients who are dying badly in spite of excellent care?

● Should we respond to individual cases in secret or create public policy?
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?

- Full exploration; Why now?
- Potential meaning of the request
  - Uncontrolled symptoms
  - Psychosocial problems
  - Spiritual crisis
  - Depression, anxiety
- Potential uncontrolled, intolerable suffering
Will You Help Me Die?

- Ensure palliative care alternative exhausted
- 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

- Proportionately accelerating opioids for pain or dyspnea
- Stopping life-sustaining therapy
- Voluntarily stopping eating and drinking
- Palliative sedation, potentially to unconsciousness
- Medical aid-in-dying (aka physician assisted death)
- Voluntary active euthanasia
SOUNDING BOARD
DEATH AND DIGNITY

A Case of Individualized Decision Making

Diane was feeling tired and had a rash. A common scenario, though there was something subliminally worrisome that prompted me to check her blood count. Her hematocrit was 22, and the white-cell count was 4.3 with some metamyelocytes and unusual white cells. I wanted it to be viral, trying to deny what was staring me in the face. Perhaps in a repeated count it would disappear. I called Diane and told her it might be more serious than I had initially thought — that the test needed to be repeated and that if she felt worse, we might have to move quickly. When she pressed for the possibilities, I reluctantly opened the door to leukemia. Hearing the word seemed to make it exist. “Oh, shit!” she said. “Don’t tell me that.” Oh, shit! I thought, I wish I didn’t have to.

Diane was no ordinary person (although no one I have ever come to know has been really ordinary). She

Reprinted from the New England Journal of Medicine
324:691-694 (March 7), 1991
Grand jury clears Quill in dying patient’s suicide

Panel discovers ‘no basis for criminal liability’

Dr. Timothy Quill is not criminally responsible for helping a dying patient commit suicide, a Monroe County grand jury decided yesterday.

At worst, Quill could have been charged with second-degree manslaughter for prescribing barbiturates to a terminally ill patient, knowing she would use them to kill herself. After a full and complete presentation, the grand jury made a determination that there was no basis for criminal charges against Dr. Quill,” District Attorney Howard Ballio told reporters.

But Ballio maintained that Quill’s actions were not in any way a precedent for future cases of doctor-assisted suicide.

“There are different areas of the country and different feelings in these areas,” Ballio said. “I don’t think anyone should look at this as carte blanche to do anything they want to do.”

Quill said yesterday he was “just plain shocked this is over.”

“Hopefully, my article and the grand jury’s decision will help fuel a more sensible debate about the role of doctors in helping terminally ill patients die,” he said during a press conference at his lawyer’s Pennfield office.

The doctor still faces discipline from the state Health Department.
Physician Aid in Dying in US: Legalization in Six States and DC

- Oregon by referendum
- Washington State also by referendum
- Montana by constitutional challenge
- Vermont by legislative action
- California by legislative action
- Colorado by referendum
- District of Columbia by legislative action
Physician Assisted Death in Canada

- Canadian Supreme Court
  - Fundamental Right to choose physician assisted death
  - Potentially includes either PAD or VAE

- Criteria included
  - “Grievous and irremediable medical condition...”
  - “Causes enduring suffering that is intolerable to the individual”

- Enacted June 6, 2016
PALLIATIVE OPTIONS OF LAST RESORT
Categories of Safeguards

- Palliative care accessible and found to be ineffective
- Rigorous informed consent
- Diagnostic and prognostic clarity
- Independent second opinion
- Documentation and review
Physician Assisted Death and other Last Resort Options

The Bottom Line

● Only sensible in context of excellent palliative care
● Currently, last resort options unevenly / unpredictably available
● All options should be subject to similar safeguards
● Open processes are ultimately more safe, predictable, and accountable than secret processes
Physician Assisted Death and other Last Resort Options

The Bottom Line

Clarity about which options are available, and under what circumstances, would be beneficial

- Reassure those who fear a bad death
- Increase responsiveness to extreme suffering
- More ability to address unique circumstances
- More accountability when suffering persists
Selected References


Selected References (continued)


Physician Aid in Dying in Vermont

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HPCANYS March 30, 2017
“Any stiffness?”
Irene’s Story

• 90 year old spit-fire, Social, Strong Faith
• Acute visual change, facial Palsy
• Provider evaluation
• MRI: mass, high risk location
• Likely Malignant, Uncertain Prognosis
• Discussion of options
• Observation
• Goals Clear: Acceptance, Avoid burden, Maintain Independence, Interest in PAD
Irene’s Story

• Progressive symptoms (visual loss, HA)
• MRI enlarging mass
• Prognosis more clear
• Hospice admission
• 2 Daughters
  – 1 supportive of PAD, 1 not
  – United in support of their mother “being in charge”
Irene’s Story

• Suffering
  – pain (DJD, HA) reasonably well managed with medication titration
  – vision loss affected reading, mobility
  – Reluctantly accepted more ADL assist
  – Reluctantly accepted wheelchair
  – Reluctantly accepted 24/7 care

• Lots of visits with Friends
• Support of Faith Community
• Grieved loss of meaningful activities
Irene’s Story

• Formal PAD request
• Spoke very open and honestly about situation
• Spent time with daughters
  – emotions, choices, understanding
• In the setting of terminal Suffering, chose date
• Said good bye to community friends
• Self ingested PAD medication
• Died Peacefully in her own home with both daughters at her side
“Suffering is experienced by persons, not merely bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity...”
It is really confusing!!!
Clinical Criteria for Physician Aid in Dying

David Orentlicher, MD, JD,1 Thaddeus Mason Pope, JD, PhD,2 and Ben A. Rich, JD, PhD3; Physician Aid-in-Dying Clinical Criteria Committee
Responding to a Request

• Listen to, Validate your patient
• Open ended questions to explore suffering
• Remind your patient about their strengths, resources
• Remember your team
  – MD, RN, APRN, Social worker, Chaplain, HHA….
  – Palliative Care
  – HOSPICE
Responding to a Request

• Explore ways to minimize suffering
• Can something helpful be added?
  – Medication, visit from chaplain, family support
• Can something that is not “helping” be stopped?
  – “Palliative” interventions
You’ve got six months, but will aggressive treatment we can make it seem like much longer
Responding to a Request for PAD

- Assess eligibility
- Assess understanding of the law
- Remind your patient of the time, process, voluntary nature of request
- Prepare them for the possibility of losing eligibility during the process
- Explore alternatives to avoid prolonged dying
Physician Aid in Dying in Vermont-Eligibility

- Terminal Illness, <= 6 month Prognosis*
- Vermont Resident, age >=18
- Under the care of a Vermont licensed Physician
- Capable of making an informed decision
- Able to self administer medication
- Able to make an informed, voluntary request
- Able to complete all requirements of the legal process
PAD in Vermont - Process, Safeguards

- 2 verbal requests to Physician, no less than 15 days apart
- 1 written request, witnessed
- Consulting Physician
- Capable, Voluntary, Informed
- Exploration of treatments for terminal condition
- Psychiatric referral if any concerns
- Opportunity to rescind request
- 48 hour waiting period before prescription written
- File report with Vermont Department of Health
Between May, 2013 and March, 2017

- 2013-2014  #2
- 2014-2015  #6
- 2015-2016  #16
- 2016-2017  #23 (partial year)
- Total of 47 Prescriptions written
- Population 626,562 (2014)
- 5,336 deaths in VT (2013)
PAD/Act 39 Resources

- https://www.compassionandchoices.org/what-we-do/doctors-to-doctors
- http://www.patientchoices.org
- http://healthvermont.gov/stats/vital-records
- http://www.vtethicsnetwork.org/pad.html
References

- http://www.ekrfoundation.org
- http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0092
March 31, 2017

Responding to Requests for Medical Aid in Dying:
Stories from Oregon

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Hospice and Palliative Care Association of New York State’s 2017 Annual Interdisciplinary Seminar and Meeting, Sarasota Springs, New York.
Consultant re end-of-life issues and options (2008 to present)
CEO Oregon Hospice Association (1988-2008)
MBA in nonprofit management
Co-investigator of research about AiD and EOL
Member of Oregon and national task forces re POLST, hospice, and EOL
Hospice caregiver
Disclosures

- I have no conflicts of interest relating to this presentation
- I voted against DWDA and for its repeal in 1994 and 1997
- I would vote for DWDA in 2017
Purpose

- Add experience-based information
  - Close data void
  - “Laboratory of the states”
- Not debate whether medical aid-in-dying is right or wrong
No longer matters
It is allowed in Oregon
Dying Oregonians choose from among all EOL options, including both hospice and DWDA
Utilization: 1,127 total
—not thousands annually as predicted

- 2016
  - 204 prescriptions
  - 133 used medication
- 1998 to 2016
  - 1,749 prescriptions
  - 1,127 used medication

http://www.public.health.oregon.gov/ProviderPartnerResources/Evaluationresearch/deathwithdignityact/Pages/index.aspx
DWDA by year, Oregon, 1998-2016 (1/23/2017)

- DWDA prescription recipients (1,749)
- DWDA deaths (1,127)
Perspective

- 627,000 Oregonians died between 1998 and 2016
- 1,127 hastened death
  - Less than .2 of 1 percent
Patient Demographics (1998-2016)
19 Years Experience
Oregon’s DWDA (1998-2016)

- Median Age 71
- 52% male
- 46% married
- 73% college educated
- 98% died at home
- 99% had insurance
- 90% enrolled in hospice

Oregon Department of Human Services February 2016
Diagnoses
Underlying Illnesses (1998-2016)

DWDA DEATHS

- Malignant neoplasms (%)
- ALS or Lou Gehrig's disease (%)
- Chronic lower respiratory disease (%)
- Heart disease (%)
- HIV/AIDS (%)
- Other (%)

DEATHS WITHOUT DWDA

- Malignant neoplasms (%)
- ALS or Lou Gehrig's disease
- Chronic lower respiratory disease
- Heart disease
- HIV/AIDS
- Other

2016 (n=133)
1998-2016 (n=1,127)
1998-2007 (n=98,942)
Underlying Illnesses (1998-2016) DWDA DEATHS

- Malignant neoplasms (%)
- ALS or Lou Gehrig's disease (%)
- Chronic lower respiratory disease (%)
- Heart disease (%)
- HIV/AIDS (%)
- Other (%)

2016 (n=133) vs. 1998-2016 (n=1,127)
A call from New York

- Gentleman interested in moving to Oregon to use DWDA
- Constant severe headaches
Patient Concerns
As related by physicians
Patient Concerns

- Losing autonomy (%)
- Less able to engage in activities making life enjoyable (%)
- Loss of dignity (%)
- Losing control of bodily functions (%)
- Burden on family, friends/caregivers (%)
- Inadequate pain control or concern about it (%)
- Financial implications of treatment (%)

1998-2016 (n=1,127)
Future Concerns Motivate Requests

When confronted with a request for PAD, health care providers should first work to **bolster the patient’s sense of control** and to educate and reassure the patient regarding management of future symptoms.

Oregon Hospice Association

Its role
OHA Board Policies

- Support right of Oregonians to choose from among all end-of-life options
- Recommend that Oregonians who ask for a prescription be referred to hospice
- Recommend that hospices admit patients considering DWDA
- Respect policies of Oregon’s hospice providers concerning DWDA
Hospices
Their role
“Participants” of DWDA

- Hospices provide hospice care
- Attending physician, consulting physician, psychiatrist, psychologist are “participants” within the DWDA
  - Protected from liability when all provisions of the Act are followed
Research

Hospice and Hastened Death

- Hospice workers’ perspective important
  - Visit patients and family caregivers often in last weeks of life
  - Can compare hospice patients who request a prescription for lethal medication with other hospice patients

- Hospice workers’ experience significant
  - Median length of stay for hospice patients in 1999 who used DWDA 7 weeks
Hospice and DWDA (1999-2016)
Dorothy

- Support group for the vision impaired
- Talk about EOL options
- Thank you letter
- Case study about a blind lady at ethics meeting
- Conflicts at inpatient hospice
  - VSED
  - PS
  - Inpatient status
Hospice Nurses: Quality of Death
*(Rated on scales of 0-9) (Ganzini et al 2003)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>VRFF (N=102) (median time to death=15 days)</th>
<th>DWDA (N=55) (waiting period=15 days)</th>
<th>P Value</th>
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<td>Suffering (0=none)</td>
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<td>Peacefulness (0=peace)</td>
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<td>Quality of death (0=bad death)</td>
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<td>8</td>
<td>0.95</td>
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</tbody>
</table>
Hospitalists
Lynn, Goldstein, Annals Int Med, 5/20/03

Sedation for Severe COPD/CLRD

Per Cent

- Want sedation for self
- Offer sedation to patient
An explanation for “very low rate of assisted” death may be the high quality of care provided by Oregon’s hospices.

- Ganzini et al, “Experiences of Oregon nurses and social workers who requested assistance with suicide”, NEJM 8/22/02


http://www.ann-jackson.com

http://www.ohsu.edu/ethics

http://www.polst.org

http://www.compassionandchoices.org

http://deathwithdignity.org

http://www.oregonhospice.org
References and Resources

- **Do Doctors' Personal Values Trump Their Patient's Needs?** Commentary, VTDigger, September 26th 2016


- Clinical Practice Guidelines for Physician Aid in Dying, submitted by the Physician Aid-in-Dying Guideline Committee (Jackson A member). Compassion & Choices, September 2013.
References and Resources (cont)

- Hedberg K, Tolle S, Putting Oregon’s Death With Dignity Act in perspective: Characteristics of decedents who did not participate, *J Clin Ethics*, Volume 20, Number 2, Summer 2009 (133-135)


References and Resources (cont)

- Ganzini, L., Goy, E., Miller, L., Harvath, T., Jackson, A., Delorit, M. Nurses’ experiences with hospice patients who refuse food and fluids to hasten death. NEJM, Vol. 349, No.4, July 24, 2003
For any questions or more information:

Visit the Compassion & Choices NY Exhibitor table

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