

Last Resort for Responding to Intractable Suffering:
What are our responsibilities and limits?

Timothy E. Quill M.D.
Center for Palliative Care and Clinical Ethics
University of Rochester

Disclosures

Timothy Quill

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Is a board member of:

- American Academy of Hospice and Palliative Medicine
- Death with Dignity National Center

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

PALLIATIVE CARE 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 Uncorrectable Limitations

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



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Limitations of Palliative Care

Prevalence of Symptoms in Dying Patients

Weakness (39-91%)	Nausea/vomit (9-44%)
Pain (49-62%)	Dysphagia (4-25%)
Anorexia (8-76%)	Confusion (9-24%)
Immobility (41%)	Pressure sores (14%)
Constipation (4-51%)	Fecal incontin. (13%)
Urine incontin. (35%)	Odors (5%)
Cough (6-45%)	



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Limitations of Palliative Care

Background Prevalence of Unrelieved Pain in Terminally Ill

Bonica: Ordinary care 32-80%

Hospice or palliative care 8-37%



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Limitations of Palliative Care

Data about Unrelieved Pain at Death on Hospice

Bruera (Edmonton): 15-37% "poor" pain control

Ventafrieda (Milan): 35% "uncontrolled" pain

Moulin/Foley (NY): 27% "poor" control

Parks (St. Christopher): 8% "severe/unrelieved" pain

NHO: 21% "severe" pain 2 days prior to death



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Limitations of Palliative Care
Data about Other Unrelieved Symptoms on Hospice

NHO

- 70% dyspnea during the last week
- 24% air hunger as "severe" or "horrible"

Oregon

- 85% of patients seeking PAS on hospice
- Unrelieved pain rarely the major reason
- Loss of control, tiredness of dying, general debility common



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TWO INTERLOCKING PUBLIC POLICY
QUESTIONS

How to improve access to and delivery of palliative care services to all 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 or create public policy?



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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



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What do Terminally Ill Patients Say?
Considering versus Pursuing PAD

988 terminally ill outpatients (except AIDS)

- 60% support PAD
- 10% seriously considering PAD

92 terminally ill inpatients (Calvary hospice)

- 17% had a high desire for PAD

In Oregon, since legalization of PAD

- 1/6 talk to their families
- 1/50 talk with their doctor
- 1/1000 deaths by PAD

Emanuel, Breitbart, Tolle



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Who Asks About Physician-Assisted Dying?

Pts with cancer, neurologic disease, AIDS

White

Western culture (somewhat)

Have medical coverage

Many have access to hospice

Back, Emanuel, Meier



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Some Data from Washington State Motivations for Seeking a Hastened Death

Illness-related experiences

- Feeling weak, tired, uncomfortable (69%)
- Loss of function (66%)
- Pain or unacceptable side effects of pain meds (40%)

Threats to sense of self

- Loss of sense of self (63%)
- Desire for control (60%)
- Long-standing beliefs in favor of hastened death (14%)

Fears about the future

- Fears about future quality of life and dying (60%)
- Negative past experience with dying (49%)
- Fear of being a burden on others (9%)

IT AIN'T PAIN, AND IT AIN'T SIMPLE

(Pearlman / Starks in *Physician-Assisted Dying*, 2004 J Hopkins Press 91-101)



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Will You Help Me Die?

Full exploration; Why now?

Potential meaning of the request

- Uncontrolled symptoms
- Psychosocial problem
- Spiritual crisis
- Depression, anxiety

Potential uncontrolled, intolerable suffering



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Will You Help Me Die?

Insure 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



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Potential Last Resort Options

Accelerating opioids to sedation for pain

Stopping life-sustaining therapy

Voluntarily stopping eating and drinking

Terminal sedation

Physician-assisted death



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Accelerating Opioids for Pain Main Elements

Opioids mainstay in severe pain management

Dose is proportionate to level of pain

Small risk of sedation, respiratory depression, death with very high doses or sudden change

Risk is minimal in usual pain management

Death, if it comes, is usually unintended



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Stopping Life-Sustaining Therapy Main Elements

Potentially life-sustaining Rx include:

- Mechanical ventilation
- Renal dialysis
- Feeding tube; intravenous fluids
- Implantable defibrillator
- Steroids; usual disease-treating measures

May be withheld, or withdrawn once started

Decision-making by patient if capable, or by family if incapacitated (based on substituted judgment)



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VOLUNTARILY STOPPING EATING AND DRINKING Key Elements

Result of active patient decision

Patient physically capable of eating

Requires considerable patient resolve

Takes one to two weeks

Does not require physician involvement

Symptom management as process unfolds



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PALLIATIVE SEDATION, POTENTIALLY TO UNCONSCIOUSNESS
Key Elements

Sedation potentially to unconsciousness, life-supports withheld
Uses benzodiazepines or barbiturates
Process usually takes days to weeks
Patient dies of dehydration or complication
Patient unaware of suffering
Combination of "double effect" and withholding of life-sustaining therapy



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PHYSICIAN-ASSISTED DEATH
Key Elements

Physician provides means at patient's request
Patient must carry out final act
Potential escape is important to many
Physician moral responsibility as an accomplice
Synonyms include:
• *physician-assisted suicide*
• *physician aid-in-dying*



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Some Data from Oregon

(Tolle S et. Al. *J Clin Ethics*. 2004;15: 111-8)

1/1000 deaths by PAD
1/50 talk with their doctor
1/6 talk to their families

MOST PEOPLE WANT TO TALK

VERY FEW ULTIMATELY ACT



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ADDITIONAL PAD OREGON DATA

- Almost all patients white
- None lacked insurance
- None motivated by financial concerns
- Most had cancer
- Records cite battles against underlying diseases
- 85% enrolled in hospice programs (all had access)
- Uncontrolled pain not the main motivating factor
 - *Most often a mix of psychosocial and physical factors*



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The Oregon Experience: The Silver Lining

Other improvements in end of life care

- High percentage of deaths at home
- High rates of hospice referral before death
- Relatively strong opioid prescribing
- State-wide approach to DNR/DNI (POLST)

A wake-up call to physicians

- Physicians attend POLST and palliative care training
- Strong physician commitment to palliative care



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Physician Assisted Death Recent Political Developments

Washington State Referendum

- Oregon style law
- Passed by a margin of 59% to 41% (November 2008)
- Implementation starts in March 2009
- First year of data similar to Oregon

Montana State Constitutional Challenge

- Strong right to privacy and personal autonomy clauses
- District court held a right to physician assisted death
- Montana Supreme Court has supported lower court decision
- Practice currently legally permitted



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PALLIATIVE OPTIONS OF LAST RESORT The Need for Safeguards

Protect vulnerable from error, abuse, coercion

Ensure access and adequacy of palliative care

Risks cited for PAS are also present for VSED and TS (as well as foregoing life supports)

Balance flexibility and accountability

Balance privacy and oversight



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PALLIATIVE OPTIONS OF LAST RESORT Categories of Safeguards

Palliative care ineffective

Rigorous informed consent

Diagnostic and prognostic clarity

Independent second opinion

Documentation and review



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Risks of "Don't Ask, Don't Tell" Policy

- Access uneven and unpredictable
- Discourages explicit conversation
- Risk of misunderstanding
- No safeguards to ensure adequate palliative care and adequacy of evaluation
- Potential bereavement problems with secrecy



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Advantages of Being Explicit about Last Resort Options

Acknowledges the problem

- Less patient and family fear
- Free energy for other more important tasks

Reinforces the physician imperative to be responsive

- Nonabandonment
- Get help if you need it!

In Oregon, most patients want to talk; very few act.

- 1/1000 die using PAS
- 1/50 talk to their doctor
- 1/6 talk to their families



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Potential Risks of Being Explicit about Last Resort Options

- Might frighten some patients
- Might lead to pressure to prematurely choose death
 - Family pressure
 - Financial pressure
- Might undermine progress in hospice and palliative care
 - Lessen commitment to address difficult suffering
 - An easy out as suffering increases
- Might undermine fundamental physician values



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PALLIATIVE OPTIONS OF LAST RESORT The Bottom Line

- Only sensible in context of excellent palliative care
- Currently, options unevenly / unpredictably available
- All options should be subject to similar safeguards
- Open processes are ultimately more safe, predictable, and accountable than secret processes



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PALLIATIVE OPTIONS OF LAST RESORT
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



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