

Palliative Options of Last Resort

Which ones, when and why...

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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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Correctable Limitations

Limited access to care

Inadequate physician training

Barriers to pain management

Reimbursement disincentives

Palliative care offered too late

Physician lack of commitment

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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%)

Pain (49-62%)

Anorexia (8-76%)

Immobility (41%)

Constipation (4-51%)

Urine incontin. (35%)

Cough (6-45%)

Nausea/vomit (9-44%)

Dysphagia (4-25%)

Confusion (9-24%)

Pressure sores (14%)

Fecal incontin. (13%)

Odors (5%)

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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

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

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Emanuel, Breitbart, Tolle



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Who Asks About Physician-Assisted Dying?

Patients with cancer, neurologic disease, AIDS

White

Western culture

Have medical coverage

Most have access to hospice

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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

Palliative sedation

Physician-assisted death

Voluntary active euthanasia

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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 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

Main Elements

Result of active patient decision

Patient physically capable of eating

Requires considerable patient resolve

Takes one to two weeks

Theoretically does not require physician involvement

Symptom management as process unfolds

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PALLIATIVE SEDATION

Main 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 life-sustaining therapy

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PHYSICIAN-ASSISTED DEATH

Main 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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VOLUNTARY ACTIVE EUTHANASIA

Main Elements

Physician both provides the means and carries out the final act

Requires request and consent from a competent patient

Physicians more reluctant about this than PAD

Requires physician presence at the time of death

Allows a response to a wider range of suffering than PAD

Illegal in US and much more likely to be prosecuted than PAD

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Some Data from Oregon

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

1/500 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
- 90% enrolled in hospice programs (all had access)
- Uncontrolled pain not the main motivating factor
 - *Most often a mix of psychosocial and physical factors*
- Relatively stable, very low rates over 15 years

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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 in US: Legalization in Four States

Oregon by referendum

Washington State also by referendum

Montana by constitutional challenge

Vermont by legislative action

(California also by legislative action now awaiting governor signature)

(New Mexico currently in flux)

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Physician Assisted Death in Canada: 2015

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”

12 months to enact a regulatory framework (February 2016)

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Legal status of physician assisted dying (PAD) and voluntary active euthanasia (VAE) in other countries as of September 2015

Country	Legal status of PAD and VAE
Netherlands	PAD and VAE legal for adults and competent children older than age 12
Belgium	PAD and VAE legal for adults; euthanasia permitted for terminally ill children of any age
Luxemburg	PAD and VAE legal for adults and children older than age 12
Columbia	PAD and VAE legal for adults
Germany	Assisted suicide is legal for competent, uncoerced adults but the German Medical Association prohibits doctors from assisting on grounds that they have a duty to rescue
Canada	PAD and VAE to be legal for adults, subject to guidelines to be established under directive from the Canadian Supreme court by February 2016; in Province of Quebec, PAD and VAE will be legal by December 2015
Switzerland	Assisted suicide legal for adults if performed by someone with no direct interest in the death; some clinics will accept foreigners

PAD: Physician-assisted dying; VAE: voluntary active euthanasia

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 other last resort options

Balance flexibility and accountability

Balance privacy and oversight

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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

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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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