

Palliative Care, Hospice and Last Resort Options: *Facing an Uncertain Future Together*

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Potential Conflicts of Interest

I have no significant financial conflicts of interest to disclose.

I have been an advocate for more open access to "last resort" options including physician assisted death to address extremes of end of life suffering.

“Western” Culture

Much more diverse than is regularly acknowledged

Rugged individualism; personal choice

Truth-telling, with an emphasis toward the positive

- *Significant cultural and individual variation*

Death as an enemy rather than a natural part of the life cycle

Families smaller and more spread out

Relatively little preventive care, but unlimited catastrophic care

Relatively little death talk

Culture of Medicine

Deification of technology

Death as a medical failure, giving up

- *Do not go gently into the night; rage, rage against the light*
- Physicians as patients often accept much less aggressive treatment

Limits of medicine vs. limits of your doctor or system

Truth telling, but shading toward the positive/hopeful

Costs are disconnected from outcomes or social norms

Background Data: Palliative Care

Inadequate pain and symptom management

Inadequate physician training in palliative care

Economic incentives promote over-treatment

Physicians overly optimistic prognostication

Only about 35% complete advance directives

Medical rituals replacing religious rituals

Infrequent, very late referrals to hospice

Healing Approaches to Serious Illness

Limits of usual conceptualization

- Curative or restorative disease-based model
- Unclear how adaptation to chronic illness fits
- Death as a medical failure

Broader model of healing

- Maintaining integration and wholeness
- Finding meaning and maintaining connection
- Opportunity for growth and closure
- Commitment to face the unknown together

Elements of Medicare Hospice Benefit

Capitated, per-diem reimbursement

Prognosis of 6 months or less

Waive rights to curative treatment

Primary care giver – not 24 hour care

Limitations of Medicare Hospice Benefit

Inherent prognostic uncertainty; late referrals

Largely restricted to cancer patients in the past

Criteria developed for very advanced dementia, CHF, COPD, frailty,...

Unavailable to those who want to continue active Rx

Primary care giver requirement

Cultural, ethnic, socioeconomic barriers

Some Challenges of the Hospice Discussion

Hospice requires a “bad news” discussion

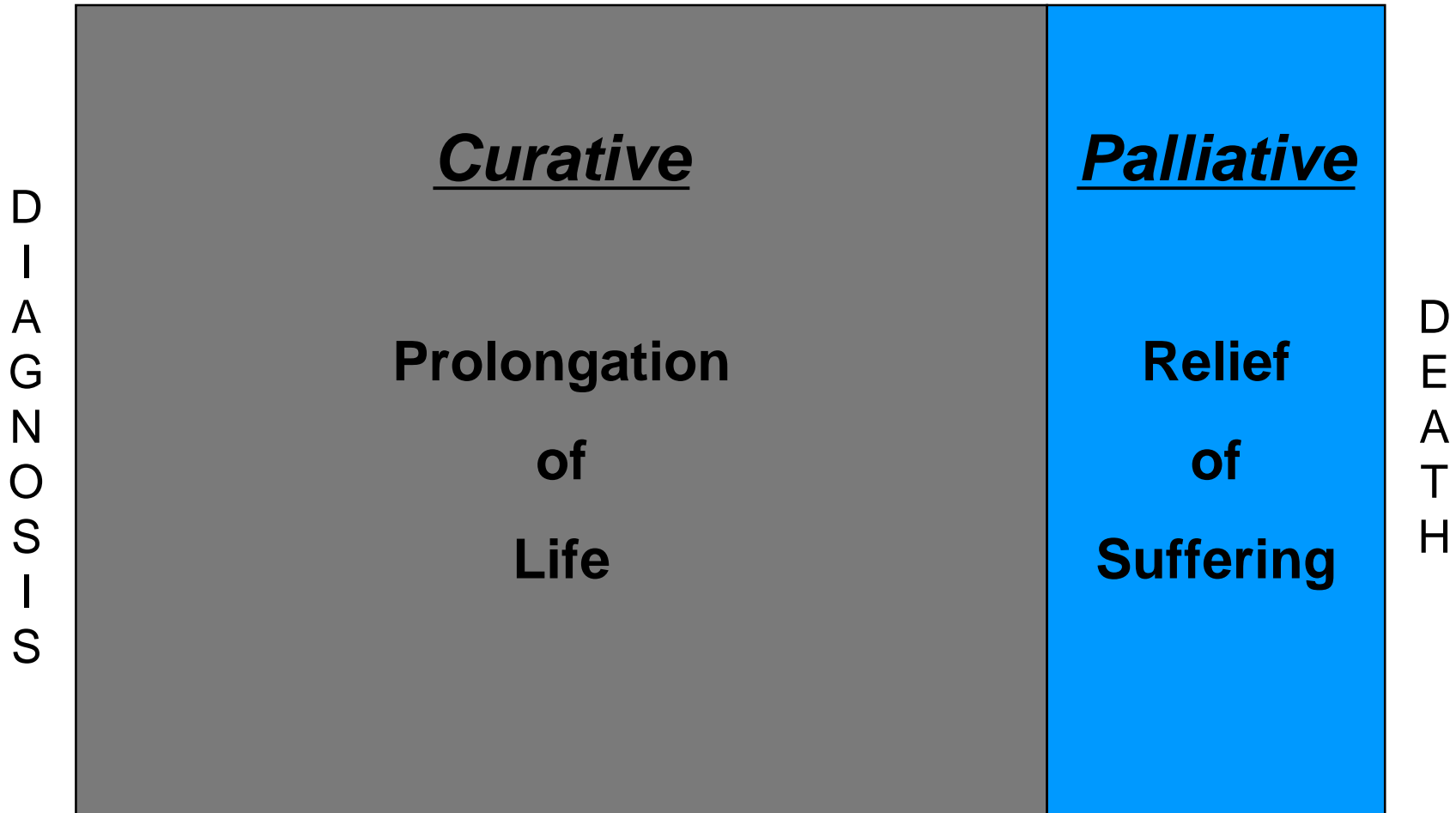
- Acceptance that medical treatment isn’t working
- Acceptance of likelihood of death in 6 months
- Giving up on hospitalization and disease-driven treatment

Many patients don’t want to stop all treatment

- May be willing to stop burdensome treatment
- May want to continue to maintain more options

Small chances of cure or longer life maintain hope

END-OF-LIFE CARE TRANSITION TO HOSPICE



As illness progresses, an increasing emphasis on palliation...



Palliative Care: *Hoping and Preparing*

"Lets hope for the best..."

- Join in the search for medical options
- Open exploration of improbable/ experimental Rx
- Ensure fully informed consent

"...attend to the present..."

- Make sure pain and physical symptoms are fully managed
- Attend to depression and any current psychosocial issues
- Maximize current quality of life

"...and prepare for the worst."

- Make sure affairs (financial/personal) are settled
- Think about unfinished business
- Open spiritual and existential issues

Like hospice, palliative care provides:

Improved pain and symptom management

Careful attention to quality of life

Fresh look at medical goals and priorities

Opportunity to consider life closure

Multidisciplinary approach

Focus on patient and family

Unlike hospice, palliative care does not require:

Forgo active treatment of underlying disease

Forgo acute hospitalization

Accept palliation as primary goal of treatment

Accept a 6-month or less prognosis

When to discuss palliative care:

Would you be surprised if patient died this hospitalization?

- Patient imminently dying
- Significant suffering and poor prognosis

Would you be surprised if patient died in 6 months?

- Significant suffering regardless of prognosis
- Patients who fear future pain and suffering
- All patients with possibly life-threatening illness

Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *NEJM. 2010;363:733-42*

- RCT of 151 patients with newly diagnoses metastatic non-small cell cancer
 - Standard oncologic care (SOC) alone
 - SOC plus early and ongoing palliative care PC (consult and monthly visits)

- Measures
 - Health related quality of life (FACT-L)
 - Mood (HADS and PHQ-9)

- Results – patients who received SOC plus PC had significantly
 - Better quality of life (FACT-L 98.0 vs 91.5; $p=0.03$)
 - Less depression (16% vs 38%; $p=0.01$)
 - Less aggressive medical care at end of life (33% vs 54%; $p=0.05$)
 - Longer median survival (11.6 vs 8.9 months; $p=0.02$)

Specialty vs General Palliative Care

General Palliative Care

- Provided by non-palliative specialist or primary care clinician
- May be alongside any and all other desired treatments
- Part of good medical care delivered by existing providers

Specialty Palliative Care

- Provided by a clinician with specialty training in palliative care
- May also be alongside any and all other desired treatments
- May require more specialized knowledge and training
- Potentially be restricted to more difficult cases
- May be consultative or primary management

Specialty vs General Palliative Care: Some clinical examples...

General Palliative Care

- Basic pain and symptom management
- Goals of care discussions
- Family meetings for decision making
- Decisions about stopping treatment or resuscitation

Specialty Palliative Care

- Complex pain and symptom management
- Major family conflict over plan of care
- Near futility discussions
- Accessing “last resort” options for refractory distress

Isn't palliative care just good medicine?

Most clinicians have not been formally trained in the basics

- Not a regular part of medical school and residency training
- Practicing clinicians are largely self taught
- May not know what they don't know
- Knowledge and skill base uneven at best

Most non-specialists do not see the most challenging cases

- Refractory symptoms unresponsive to basic treatments
- Invasive symptom management measures
- Severe depression and hopelessness
- Wish to die

Some Difficult Questions

"Should I try experimental therapy?"

"Is it time for hospice?"

"How can hope be preserved?"

"Will you help me die if my suffering becomes unacceptable?"

Should I try experimental therapy?

It might work!

Avoids the sense of “giving up”

Contributes to future knowledge

He has always been a fighter!

Why not try experimental therapy?

May medically define the last stage of life

May avoid important discussion and planning

Spend precious time in hospitals with doctors

More symptomatic from side effects

Experimental Therapy: *Finding a Balance*

If it is non-toxic, why not? Explore the details

Explore the patient's values and preferences

Both hope and prepare

Not all miracles are medical

Share your experience and recommendations

Is it time for hospice?

Goal is primarily palliation

- No acceptable disease treatment options available
- Experimental treatment not promising

Some serious advantages

- Much more support at home – 2-4 hours per day
- Payment for medications and durable goods
- Support of a multidisciplinary team
- Focus on patient and family
- 24 hour back-up at home

Is it time for hospice?

But it is usually a hard transition...

- Disease treatment not working
- More likely than not to die in next 6 months
- Most likely forgo aggressive life prolonging therapy

Most patients and families very satisfied

- Intensive multidisciplinary focus on quality of life
- Care in one's own home if at all possible
- Good back up systems

Hospice requires a “bad news” conversation

More likely than not to die in the next 6 months

Disease-directed therapy not likely to help

All treatments must be palliative in intent

Hospitalizations only for hard to control symptoms

What about if I get an infection that might respond to IV treatment?

What if I get dehydrated and I need some IV fluids to keep going?

What if...

Preserving Hope

Medical avenues of hope

- Breakthrough from traditional treatment
- New or experimental treatment
- Enhancing quality of life through palliative treatment

Non-medical dimensions

- Spiritual or religious
- Family
- Alternative therapies
- New and different personal goals

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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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

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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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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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Will You Help Me Die, *NOW*?

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, potentially to unconsciousness

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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VOLUNTARIY ACTIVE EUTHANASIA

Main Elements

Physician provides means at patient's request

Physician carries out final act (at the patient's request)

Physician moral and legal responsibility greater than PAD

Legal repercussions in US much more stringent than PAD

Recently legalized in all of Canada

Legal in the Netherlands and several European countries

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Some Data from Oregon

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

1/300 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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Physician Assisted Death in US: Legalization in 7 States and DC

Oregon, Washington State and Colorado by referendum

Vermont, Washington DC, California and Hawaii by legislative action

Montana by court ruling

Legislative activity currently under consideration in about 20 states

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Physician Assisted Death in Canada: 2018

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”
- Death being “reasonably foreseeable”

Enacted June 6, 2016

Data just beginning to be collected

Current legal challenges around terminality requirement

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Legal status of physician assisted dying (PAD) and voluntary active euthanasia (VAE) in other countries as of June 2016

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 (not by physicians) is legal for competent, uncoerced adults, but the German Medical Association prohibits physicians from assisting on grounds that they have a duty to rescue
Canada	PAD and VAE legal for adults, subject to guidelines established under directive from the Canadian Supreme court as of June 6, 2016
Switzerland	Assisted suicide legal for adults if performed by someone with no direct interest in the death; some clinics will accept nonresidents

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

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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 PAD 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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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 Care The Bottom Line

Palliative care should be part of the plan for all seriously ill patients

- *Don't wait for it until there is a drastic need!*

All clinicians who care for seriously ill patients should know how to do basic palliative care

Specialist palliative care backup is available to help manage more difficult symptoms and help with more challenging decision-making

Challenge is to use medicine's full potential in an individualized way

Hospice

The Bottom Line

The premiere program providing palliative care for terminally ill patients and their families

Very hard transition for many patients and families

Yet most are very appreciative once transition is made

More help at home than any other home care program; can also be provided in nursing homes and hospice houses

Most patients can find a meaningful and relatively peaceful death on hospice, but there still may be challenges

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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Using Medicine in an Individualized Way

Privilege to work with patients like Cynthia

Make best possible decisions in the face of tragedy

Importance of honest/humane communication

May have to talk about death and dying while fighting vigorously for life

Always keeping the values of the patient and family in the forefront of medical decisions

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