

Palliative Medicine 101: Understanding the Role of Palliative Care in the Community

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Palliative Care: Definition

- Palliative – Mitigating, reducing the severity or alleviation of symptoms without curing the underlying disease
- Care – application of knowledge to the benefit of a community or individual
- Stedman's Medical Dictionary, 25th Edition

Palliative Care

- Palliative care is the medical specialty focused on improving quality of life for people suffering from serious illness. It is appropriate at any stage of an illness. And it can be delivered at the same time as treatment that is meant to cure.

The Nature of Suffering and the Goals of Medicine - Eric J. Cassell

The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Physician training . . .

- No formal training
- Physicians feel ill equipped
- “They said there was ‘nothing to do’ for this young man who was ‘end stage.’ He was restless and short of breath; he couldn’t talk and looked terrified. I didn’t know what to do, so I patted him on the shoulder, said something inane, and left.”
- “At 7 am he died. The memory haunts me. I failed to care for him properly because I was ignorant.”

The Cure - Care Model:

**Life
Prolonging
Care**

**Palliative/
Hospice
Care**

D

E

A

T

H

Disease Progression

The diagram illustrates the 'Cure - Care Model' of medical care. A horizontal red arrow at the bottom points to the right, labeled 'Disease Progression'. A vertical magenta line intersects this arrow. To the left of the line is the text 'Life Prolonging Care' in blue. To the right of the line is the text 'Palliative/Hospice Care' in blue. On the far right, the letters 'D', 'E', 'A', 'T', and 'H' are stacked vertically, corresponding to the progression of the disease.

Knowledge Base Deficiencies

- Natural history of disease is not emphasized
- Little experience

*Therapies to
Modify disease*

*Hospice
Benefit*



Palliative Care

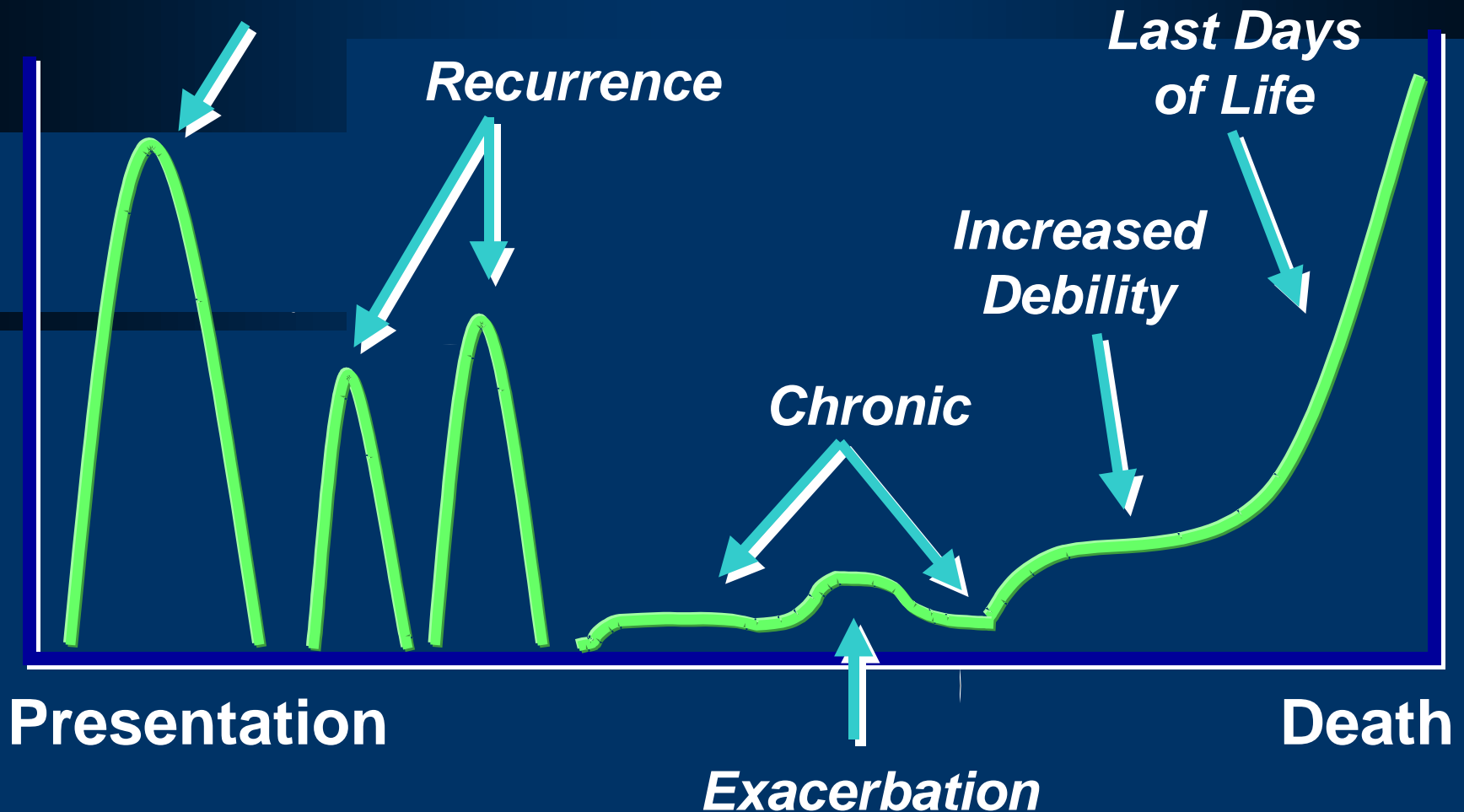
Presentation

6m Death

*Therapies to relieve suffering
and improve quality of life*

*Bereavement
Care*

Palliation may be provided as needed...



What are we fighting, what is the enemy of modern medicine??

- Death?? No!!
- Suffering, disability and loss of independence
- Patients will need to be treated based on values and goals of care rather than diseases

What Do Patients With Serious Illnesses Want?

What Do Patients With Serious Illnesses Want?

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Avoid functional dependence
- Strengthen relationships with loved ones

Singer et al, JAMA 1999

Pain data from SUPPORT

% of 5176 patients reporting moderate to severe pain between days 8-12 of hospitalization:

colon cancer	60%
liver failure	60%
lung cancer	57%
MOSF + cancer	53%
MOSF + sepsis	52%
COPD	44%
CHF	43%

Desbiens & Wu. JAGS 2000;48:S183-186.

SUPPORT: Phase I Results

- 46% of DNR orders were written within 2 days of death.
- Of patients preferring DNR, <50% of their MDs were aware of their wishes.
- 38% of those who died spent >10 days in ICU.
- Half of patients had moderate-severe pain >50% of last 3 days of life.

Started inpatient because everybody with serious illness spends at least some time in a hospital...

- 98% of Medicare decedents spent *at least some time* in a hospital in the year before death.
- 15-55% of decedents had *at least one stay* in an ICU in the 6 months before death.

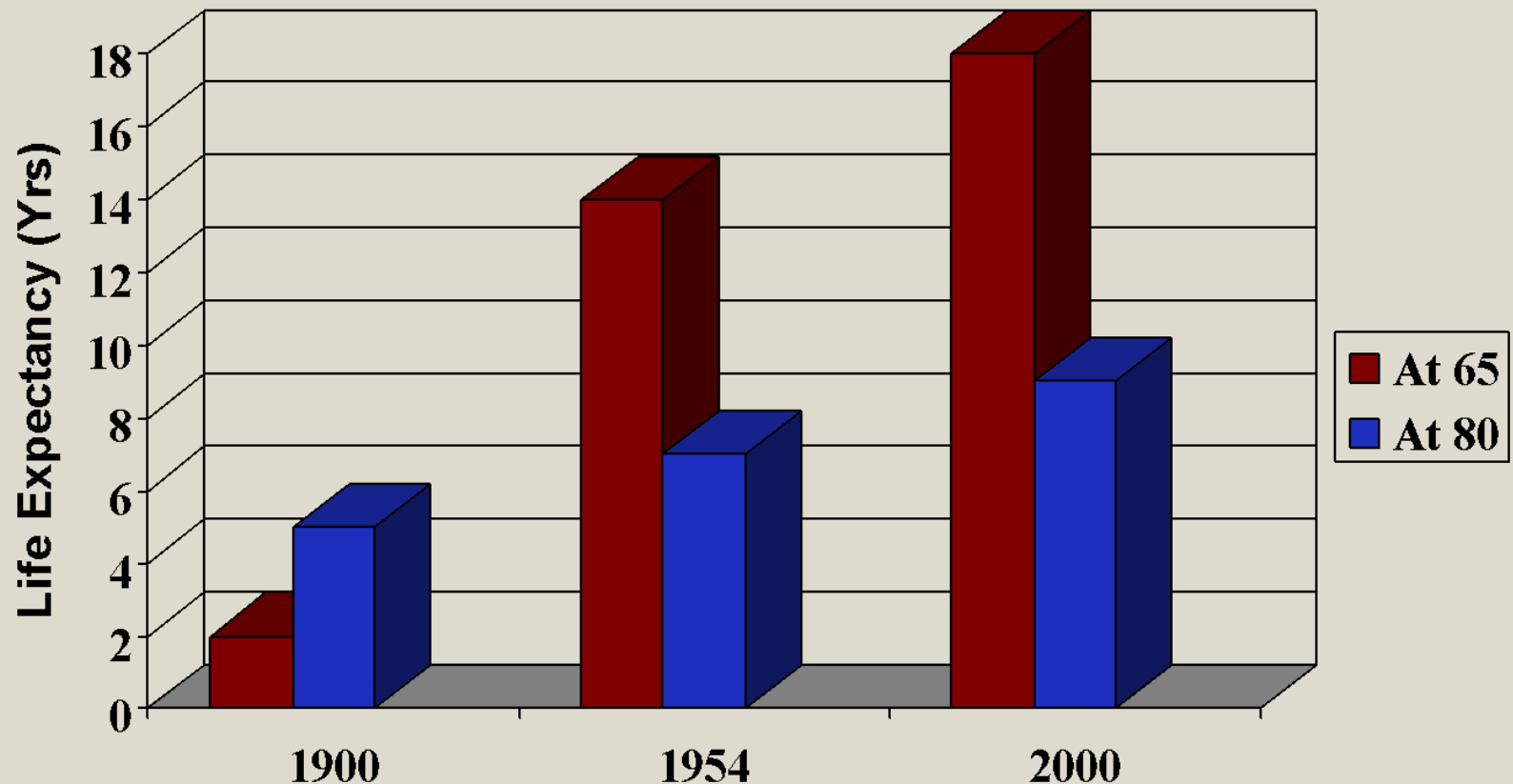
Dartmouth Atlas of Health Care 1999

The demographic imperative:

A Growing chronically ill, aging population

- The number of people over age 85 will double to 9 million by the year 2030 (CDC)
- Aging baby boomers will demand better care for their parents, then for themselves
- Data show caregivers are severely burdened financially, emotionally, and physically (JAMA)
- System patterns, silo payment incentives promote acute episodic care, but patients will need a continuum of care over years of illness
- Health care reform

Average Life Expectancy



Challenges in Providing Palliative Care: Referring Providers

- Lack of familiarity with the increasing knowledge in physiology and symptom management
- Medical encounters increasingly focused - Goals are disease treatment and are curative
- “Hot potato syndrome”
- Communication skills training
- Cultural diversity in approach to end-of-life issues
- Uncertain of role in the care of the dying patient and sense of failure
- Unfamiliar with palliative care and potentially hospice services

Challenges in Providing Palliative Care: Our Perspective

- Unfamiliar with palliative care consultation and hospice services
 - How they overlap
 - How they are different
 - What's our expertise and what can add to the care
 - Conflict resolution
- Medical encounters increasingly focused and short length of stay
 - Significant role for continuity
- Cultural diversity in end-of-life care
- “Death people”, “Death Panels” – DNR-CC

Patient Benefits

For patients, palliative care is conduit to:

- relieve symptom distress: pain, nausea, breathlessness, anxiety, depression, fatigue, weakness
- navigate a complex and confusing medical system
- form and understand a plan of care
- help coordinate and control care options
- allow simultaneous palliation of suffering along with continued disease modifying treatments
- provide practical and emotional support for exhausted family caregivers
- “how people should be treated” vs “saving lives is just the beginning” vs “hopes and miracles”

Medical Provider Benefits

- Save time by helping to handle repeated, intensive patient-family communications, coordination of care across settings, comprehensive discharge planning
- Bedside management of pain and distress of highly symptomatic and complex cases thus supporting the treatment plan of the primary physician
- Advance directives and prognostication
- Promote patient and family satisfaction with the clinician's quality of care
- Teaching next generation of medical providers

Staff Benefits

- Having the support to discuss treatment goals and symptom management issues with medical staff
- Empowerment via increased knowledge
- Take the lead in symptom management
- Job satisfaction
- Humanism



Leads to better care for all patients in the hospital

Hospital Benefits

- Effectively treat the growing number of people with complex advanced illness
- Provide service excellence, patient-centered care
- Increase patient and family satisfaction
- Improve staff satisfaction and retention
- Meet JCAHO quality standards
- Rationalize the use of hospital resources
- Increase bed/ICU capacity, reduce costs

Palliative Care...

- Affirms life, sees death as a personal and natural process
- Many diagnoses -“serious or life threatening illness”
- Patient and family preferences sought and respected
- Appropriate early in course of illness combined with life prolonging therapies or may become the focus of care near the end of life
- Interdisciplinary
- Psychological, spiritual, social, bereavement support

Who is candidate for referral?

- **Presence of a serious, chronic illness:**
 - Declining ability to complete activities of daily living
 - Weight loss
 - Multiple or frequent hospitalizations
 - Difficult to control physical or emotional symptoms
 - Patient, family or physician uncertainty regarding prognosis or goals of care
- Limited social support and a serious illness (e.g. homeless, chronic mental illness)
- Request information regarding hospice
- Patient or family psychological or spiritual distress

Palliative Medicine at Cleveland Clinic

- Inpatient
 - Main Campus, Hillcrest, South Pointe, Fairview, Medina
 - Marymount coming soon!
- Outpatient
 - Office-based: MC, Hillcrest, Fairview, Twinsburg.
 - Avon coming soon!
 - Home visits, nursing facilities

The Patient's Good and the Ends of Medicine

If medicine takes aim at death prevention, rather than at health and relief of suffering, if it regards every death as premature, as a failure of today's medicine-but avoidable by tomorrow's- then it is tacitly asserting that its true goal is bodily immortality... Physicians should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine.

Kass LR. JAMA 1980;244:1947

Thank You!