

IMPROVING CARE at END-of-LIFE by PALLIATIVE CARE and HOSPICE

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Objectives

- Become more comfortable with Dying and Death
- Deficiencies in End-of-Life Care
- Hospice and Palliative Care
- Managing Symptoms Safely in Dying Patients
- Educating Healthcare Professionals and the Community

Ethical Principles

Autonomy: respect for patient's choice

Beneficence: do good

Non-maleficence: don't harm

Justice: fair use of resources

Death and Dying: Ways to Die

- Sudden death, unexpected cause
- Steady decline, short terminal phase (cancer, ALS, advanced life-threatening disease)
- Slow decline, periodic crises, death difficult to predict (organ-failure, frailty)

Death Anxiety

- Death is a primordial source of anxiety- we all have it deep within us.
- Most of us convert it to something less threatening by denial, or transference
- One person may choose to believe in his/her specialness and inviolability; another may believe in an ultimate rescuer. We all prefer not to think about death- for us, our families, and our patients

Confronting the Reality of Death

- Kubler- Ross: denial, anger, bargaining, depression, finally acceptance
- Loss of control: of function and independence, of decision-making capacity, and of dignity
- Life Review: What have I made of my life?
- How do I want to be remembered?
- Healing relationships with family and friends (before it's too late)

Death Anxiety in Patients

- Death anxiety is inversely proportional to life satisfaction:
- “When life had appeared satisfying, dying was less troublesome... lesser satisfaction with past life went with a more troubled view of the illness and its outcome” John Hinton, in Yalom, Irvin: Death, Anxiety, and Psychotherapy; The Yalom Reader (1998) 260.

Final Days of a Good Death

- Gradual decline in ability to perform ADLs
- Loss of weight (cachexia)
- Fatigue
- Anorexia
- Diminished thirst
- More time in bed

Normal dying: Shutting down

- Loss of appetite
- Diminished thirst (keep tongue moist)
- Artificial food / fluids may make situation worse
 - breathlessness/ aspiration
 - edema
 - ascites
 - nausea / vomiting

As death nears, patients may exhibit the following:

- Sleep more
- Speak to people not present
- Talk about leaving or taking a trip
- Withdraw from people, talk less
- Eat or drink less
- Have trouble swallowing
- Become more confused

....and finally

- Lose control of urination and BMs
- Have moist breathing or sound congested
- Have changes in the breathing pattern:
irregular, long pauses
- Have blurred vision and not hear well
- Much less responsive, deeply asleep, coma

“Changing Gears”

Try to notify the family early of decline, and teach the family what to look for very near the end:

- Rattling, noisy breathing
- Cold extremities
- Skin mottling
- Patient unrousable
- Irregular breathing – agonal breathing

Good Finish for a Peaceful, Comfortable Death

You are important to me. (I love you)

Forgive me.

I forgive you.

Goodbye.

Grief and Bereavement

- To deal with loss of any kind, one must:
- A) Accept the reality of loss
- B) Experience the pain caused by the loss
- C) Adjust to the new environment after the loss
- D) Rebuild a new life
 - Hospice provides bereavement followup for 13 months

End of life in America today

- Modern health care
 - only a few cures
 - live much longer with chronic illness
 - dying process also prolonged

II . Problems with End-of-Life Care

- Families and patients often complain about:
- Poor Communication: Talk to Us!
- Respect my Wishes! Give us some control.
- Don't abandon us! We expect you there.
- Help relieve our Suffering and our Pain. We suffer emotionally and spiritually too!

Satisfaction with Hospitals as Last Place of Care

- 2000 Mortality follow-back survey, n=1578 decedents: (Diane Meier, CAPC)
- Not enough contact with MD: 78%
- Not enough emotional support (pt): 51%
- Not enough information about what to expect with the the dying process: 50%
- Not enough emotional support (family): 38%
- Not enough help with pain/SOB: 19%
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2000- 2010

Improvements in Care

- Communication skills are better
- Advance directives are evolving (POLST)
- More emphasis on outpatient care
- Hospice and Palliative care electives and rotations
- More use of interdisciplinary teams for treating the chronically ill elderly population

“Talk to me and my family”

- Keeping the patient and family informed enhances a stronger doctor-patient relationship (and reduces the risk of litigation).
- Listen: “ if you listen carefully to what patients say, they will often tell you not only what is wrong with them but also what is wrong with you” Walker Percy :” Love in the Ruins”
-

“Talk to me and my family”

- Breaking Bad News:
- Set the stage
- What does the patient and family know?
- What do they want to know?
- Give the news, pause, await the reaction
- Establish a plan of action
- Answer questions , pledge support

Communication

- A study in 2007 asked patients waiting to see their doctors: “What should doctors learn as part of continuing medical education?”
- Patient’s answer: 12% science; 56% communication skills
- Doctor’s answer: 90% science; 0% communication skills
- Arnold, R: Formal, informal, and hidden curriculum in the clinical years: Where is the problem? J Palliat Med 2007; 10: 646-648

Advance Directives

- Living Will
- DPOA: Durable Power of Attorney for Health Care
- POLST: Physician Orders for Life-Sustaining Treatment

“Don’t Abandon Me”

- “There’s nothing more we can do” is often perceived by patients, rightly or wrongly, as abandonment
- This is a time of great vulnerability
- Knowing that someone they trust and rely on will be there for them, whether for aggressive or for supportive care is crucial

Why Hospice?

Why Palliative Care?

- Attitudes
- Delivery of Care
- The SUPPORT study in the 1990s
- AAHPM: American Academy of Hospice & Palliative Care
- EPEC: Educating Physicians in End-of-Life Care
- CAPC: Center to Advance Palliative Care

Inadequate Training of Healthcare Professionals

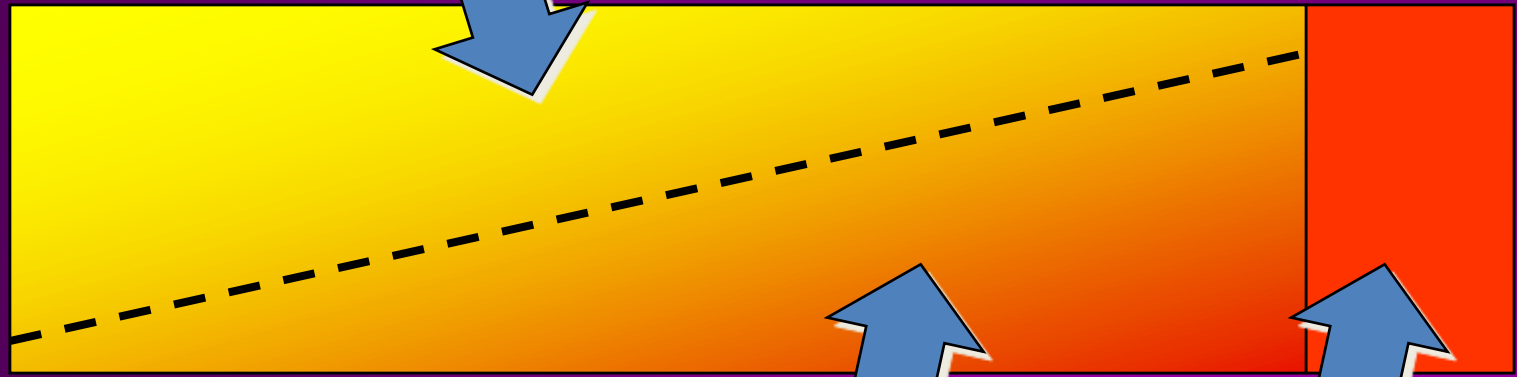
- Doctors and Nurses not taught how to care for patients as they die- not in school and not in training
- Emphasis has been to diagnose and treat DISEASE rather than on caring for PEOPLE
- Traditional model of medical care not suited to needs of the suffering chronically ill with loss of function, independence, and control.

- Definitions: Palliative care focuses on relieving symptoms causing suffering of patients (pain, dyspnea, etc) earlier in the disease, and assists patients and families make difficult decisions about care.
- Hospice takes a holistic approach and addresses their physical, emotional, and spiritual needs. Both communicate with and offer support to patient's families.

New Definition of Palliative Care

- Palliative Care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering
- Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.
- Palliative Care is NOT End-of-Life Care and is not dependent on prognosis. (Medicare)

Curative / remissive therapy



Presentation

Death

Palliative care

Hospice

Medicare Hospice Benefit (established 1982)

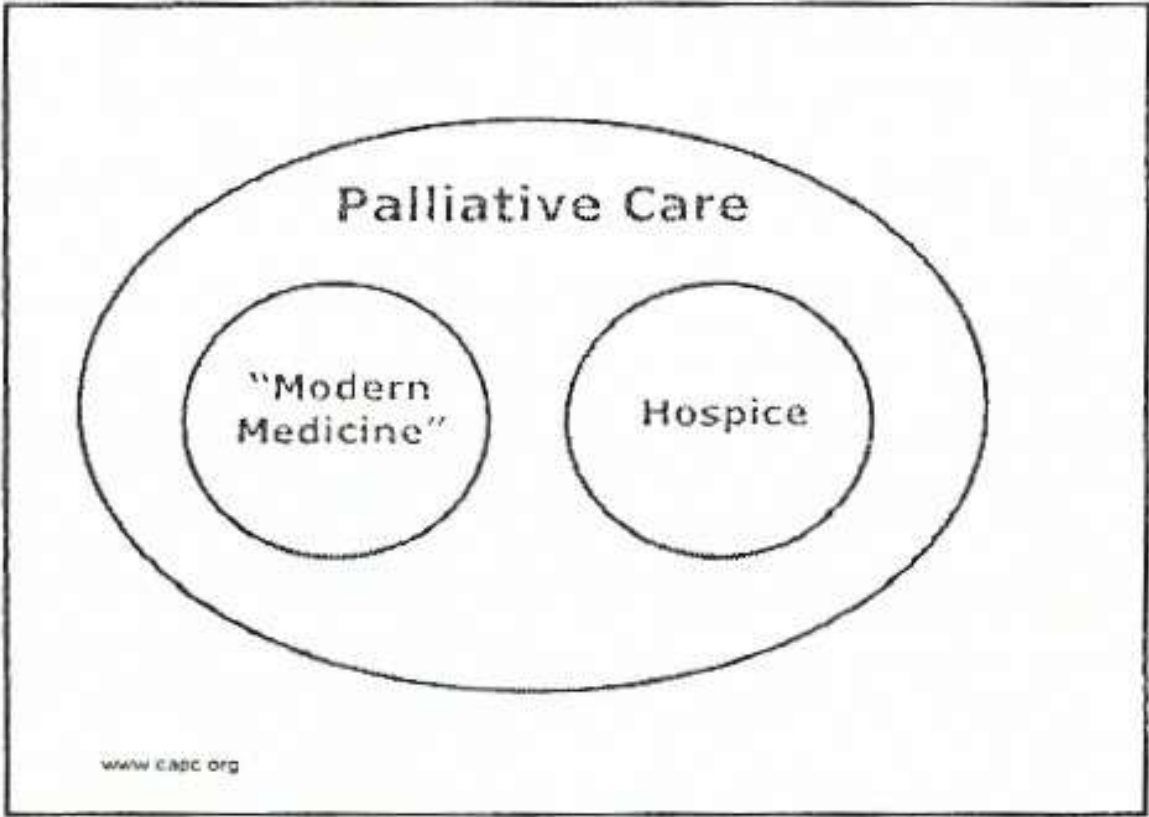
- Certified organization (non-profit or for-profit)
- Receives a capitated fee (approx. \$120 daily per patient) to provide care to qualified patients, usually at home
- Pays staff salaries, overhead, durable medical supplies, medications for admitting condition

Hospice Medicare Benefit

- Patient must have 6 mo. prognosis if disease follows expected course; some live longer- can recertify if still qualifies
- Request to enter usually by MD; patient or family can request admission
- Hospice is a choice- can revoke anytime
- Provide bereavement support after death for family, for 13 months

The Problems with the Medicare Hospice Benefit

- Concept was based on care for cancer patients
- Removed hospice from mainstream medicine
- Required patients and families to cease aggressive care
- Results: late referrals or no referrals



The Hospice Team

- The Nurses: Director, Patient Care Coordinator, and Nurses qualified in EOL care
- Certified Nursing Aides
- Social Workers
- Chaplain and Bereavement Coordinator
- Compounding Pharmacist
- Volunteer Coordinator and Volunteers
- Medical Director

Hospice Service

- Referral visit- to explain program
- Admit by RN- assessment , sign papers
- Establish treatment plan, schedule RN, CNA visits
- Visits by other team members (within 72 hrs)
- Nurse available 24/7; others as needed
- Re-assess q 2 weeks by entire team
- Re-certify in 90 days, then every 60 days if still qualifies

Palliative Care Programs

- Most academic institutions, tertiary treatment centers, large teaching and many smaller community hospitals now have consult programs, some with inpatient units.
- To maintain continuity of care, some have outpatient clinics and/or home visitation.
- Training of Palliative Medicine will only be by a 1 yr. fellowship after 2012.

Why is Palliative Care Important to Health Care Reform?

- >95% of all healthcare spending is for the chronically ill.
- 64% of all Medicare spending goes to the 10% of beneficiaries with 5 or more conditions.
- Despite spending, evidence indicates that quality of care is poor.
- There are 37.5 million beneficiaries. Total Medicare spending: \$265 billion. In 10 years,
- CAPC estimates saving \$60 billion/yr with PC.

Mortality follow back survey: palliative care vs. usual care N=524 family survivors

Cassarett et al. J Am Geriatr Soc 2008;56: 593-99

- Overall satisfaction markedly superior in palliative care group. $p < .001$
- Superior for: emotional/spiritual support
information/communication
care at the time of death
access to services in community
well-being/dignity; pain
PTSD symptoms

“Symptom Relief Kit”

Morphine solution 20mg/ml (15ml): pain, dyspnea

Chlorpromazine suppository 25mg (2): agitation, nausea

Phenergan suppository 25 mg (2): nausea, vomiting

Tylenol suppository 500 mg (2): fever

Atropine eye drops 1% 15 ml: terminal secretions, or

Hyoscyamine [1-atropine] tab 125mcg (4)

Lorazepam Conc. Sol., 2mg/ml(buccally) (15ml):
anxiety; seizures

Haloperidol tabs 2mg (6): delirium, agitation, nausea

Safe and Effective Treatment of Major End-of-Life Symptoms

- Pain and Dyspnea: MS oral concentrate sol. 20mg/ml: 0.25 (5mg) q 2-4 hr prn buccally; titrate up gently.
- Anxiety, panic, agitation: Lorazepam oral conc. 2mg/ml: 0.5 ml (1mg) q2-4 hr prn; titate up or down. If agitation worsens, switch to Haloperidol conc. 2mg/ml: 0.5-1ml (1-2mg) po or buccally.
- Rattling secretions: Atropine 1% sol: 1-2 drops

Improving Care

- Educate everyone:
 - Academic institutions
 - Healthcare students, trainees, professionals
 - Patients, families
 - Community
 - National decision-makers

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