Palliative Care Past, Present, and Future

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Dying at home with family

“In America, death is seen as optional”
Woody Allen
Paul – “My Back!”

Advanced Lung Ca
Severe back pain
Leg weakness
Fear of dying
Financial stress
Family problems
Hopelessness, “Why me?”

Palliative Care

- Active, total care of patients whose disease is not responsive to curative treatment.
- Goal is best possible quality of life for patients and families.
- Affirms life and regards dying as normal.
- Symptom relief & psycho/spiritual support.
- Support system to help family cope.

Palliative Care and Hospice
Dame Cecily Saunders
Nurse, then Social worker, Inspired by dying immigrant
On to Medical School
Worked in St Joseph’s Hospice
Developed pain and symptom management
Opened St Christopher’s Hospice in 1967
Randomized trials, clinical excellence, compassionate care

First Things First
- “Any group concerned with service to the dying should be talking about smoothing sheets, rubbing bottoms, relieving constipation, and sitting up at night…”
- “Counseling a dying person who is lying in a wet bed is ineffective.
- “Such concerns loom large in the lives of critically ill patients, and must be of importance to the physician if the physician is to treat the whole person.

Lack, SA The Hospice Concept, Proceedings of ACS, 1977

The way care is given…
Total Pain

- **Physical** – often multiple, treatable cause?
- **Mental** – anxiety, depression, suffering
- **Interpersonal** – isolation, unfinished business, anger
- **Financial** – unworthiness, caregiver stress
- **Spiritual** – “dysfunctional theology,” meaning, hope
- **Staff stress** – need for self-care, renewal

Search for Reversible Causes

- “He stopped taking all his medications yesterday and now he is so restless…”
- “All agitation is due to a blocked Foley catheter or a fecal impaction until proven otherwise!”

Getting the dose right
Caring, attentive follow-up

Getting the Meds into the Patient

Mental Pain
Anxiety and Depression

- Normal parts of dying and grief
- Many fears can be addressed – uncontrollable pain, dyspnea, etc.
- Helped by
  - alleviating problem
  - centered presence
  - skilled counseling
  - medication
**Interpersonal Pain**

- Loneliness / Isolation
  - fear of:
    - Misery, stench
    - Anxious, needy
    - Hopeless, depressed
- Relationship Issues
  - Not "the way's supposed to be"
  - Unworthiness, guilt
  - Old wounds, anger

**Financial Pain**

- Getting the needed
  - Medications, treatments
  - Care at home
  - Support for caregivers
- Guilt and Fear
  - Being "a burden"
  - Self-image of independence

**Spiritual Pain**

- "Dysfunctional" theology

  **Beliefs about God that induce suffering:**
  - **Cure is certain, if...**
    - "If only you have enough faith..."
  - **Pain is punishment for sins**
    - "God is just... do you have a confession to make?"
  - **Suffering is from God**
    - "All things...for good...to them that love God."
    - "Mommie is going to be with Jesus..."
Competent Pastoral Care

Baby Boomers: Coming of Age

- By 2010, America’s 77 million baby boomers will begin turning 65
- America’s population over the age of 65 will double by the year 2020.

Aging and Medical Care

- Family caregivers are severely burdened financially, emotionally, physically (JAMA)
- Medicare patients with 2 or more chronic conditions account for 95% of Medicare spending (CDC)
- 76% of 2002 Medicare budget was spent on hospital care ($198 billion)
- Baby boomers will demand more
Death in the hospital: What do we know about it?

- Physical suffering
- Poor to non-existent communication about the goals of medical care
- Lack of concordance of care with patient and family preferences in almost 50%
- Huge financial, physical, and emotional burdens on family caregivers
- Suffering of professional caregivers
- Fiscal impact on hospitals

Quality of Life at the End of Life: What Patients and Families Want

- Pain and symptom control
- To avoid inappropriate prolongation of the dying process
- To achieve a sense of control
- To relieve burden on family
- To strengthen relationships with loved ones

Singer et al, JAMA 1999
“Take me home!”

• 90% of adults prefer to be cared for in their own home if terminally ill
• Nearly 75% of Americans currently die in hospital or nursing home facilities.

Common Reasons for Hospital Palliative Care Consultation

- Clarification of patient and family care goals
- Pain and symptom management
- Emotional, social, and spiritual support
- Coordination of terminal care and/or facilitating hospice referral
- Withdrawal of life-sustaining therapies including mechanical ventilation, dialysis, nutrition and hydration

Inpatient Consultation: Examples

- 47 y/o man w/ advanced colon cancer and severe pain; on 10 mg/hr hydromorphone
- 34 y/o female admitted with a large hemorrhagic stroke; family unsure
- 87 y/o male with advanced dementia admitted w/ new hip fracture; not eating
Pain is Bad for You!
- Depression, thoughts of suicide
- Sleep disturbances, decreased quality of life
- Impaired ambulation, falls, blood clots
- Confusion, agitation, & restlessness
- Shallow breathing, pneumonia
- Longer time in hospital, higher rate of death
- “No effective counseling occurs in a wet bed.” – Sylvia Lack

Pain makes everything more difficult

Mount Sinai Hospital: Improvement in Symptoms for 1070 Patients Followed by the Palliative Care Service (6/97-12/01)
Family Support

Mount Sinai Hospital: Impact of Palliative Care Program on ICU Transfers and Hospital Discharge in 2000

- Patients who died in hospital with palliative care spent 3.8 fewer days in ICU as compared to those not followed by palliative care
- 100 patients were transferred from ICU to palliative care
- 200 (40%) of patients followed by palliative care were discharged home to hospice
- Hospice referral rate increased by 300% in first year of palliative care program

Source: MR review & hospital database
Fiscal impact of Mount Sinai clinical service: length of stay analyses in 1999

- Median length of stay of patients who died at Mount Sinai without palliative care = 27.6 days
- Median length of stay who died at Mount Sinai with palliative care = 25 days
- Result = hospital salary support for a doctor and a nurse for the palliative care service

Meier, D. Planning a hospital-based palliative care program: A primer for institutional leaders. www.capcmssm.org

Inpatient Palliative Care Services
KP Randomized Controlled Trial

- 512 patients, multi-site (N=250 Colorado)
- Improved pain control, ↓ anxiety, burden
- Greater pt/family satisfaction with care
- Decreased utilization and costs
  - ↓ Hospital admissions, ICU, ER visits
  - Increased outpatient utilization, hospice LOS
  - Inpatient program savings $6,600 per patient
  - Estimated cost savings 2005 ~ $5 million

"Impact of an inpatient palliative care service: a randomized controlled trial"


Total Service Costs

- Program enrollment, adjusting for age, disease severity of illness, and days on service, explained 16% of the variance in total service costs
- Adjusted costs of care for those in PC were 37.8% less than those receiving UC

Site of Death (n=217)

Studies show that most people prefer to die at home*.
Patients enrolled in the Palliative Care program were significantly more likely to die at home.


“I’m so glad we made it home!”

Growing Palliative Care Services

Clinic-based PC Team

Inpatient PC Team

Home-based PC Team

NH/LTAC PC Team

Special Services

Denver Hospice

Boulder Hospice
The hospital of the future will have a palliative care program

- Palliative care improves quality of care for sickest and most vulnerable patients and their families.
- Hospital lengths-of-stay, costs of care, and complaints about symptom management can all be effectively reduced, for a small investment.
- Nationally:
  - Palliative care emerging standard of care
  - Nearly 1100 hospitals nationwide w/ PC (63% growth since 2000)
  - 14/15 top hospitals (2004 US News & World Rep)

Logotherapy -- Finding Meaning

- What have you built?
- Whom have you loved?
- What have you achieved?
- What do you leave behind?

Logotherapy – Choices

- What is my problem?
- What is my area of freedom?
- What choices do I have?
- Which possible choice is most meaningful?
- Which choice will I bring into reality?
I believe that every individual has the potential within, to meet death with a severe beauty which in no way denies grief.

Being alongside such families, you absorb some of their grief.
But you also share some good things
- Learning to think of time in terms of depth rather than length,
- Enjoying the swift growth of real friendship,
- Bypassing the usual obstacles of class, creed, colour, age, education,
- Having “all one’s sensitivities heightened”

And you begin to recognize and reverence the nobility and beauty in every man, woman, and child because tragedy lifts the mask of pretense and truth is revealed.

Wounded Healer
- Wounding & Loneliness
- Wounding as a source of healing
- Hospitality
  - Welcoming our own pain
  - Welcoming others
  - Sense of community
Our Search for Meaning
by Cicely Saunders

- The work will at times cause pain and bewilderment...
- Those who commit... develop a basic philosophy...
- This Search for Meaning can create a climate where patients and families can reach out in trust, towards what they see as true...