Policy Issues for End of Life Care
Monday March 19, 2012
10:45 am – 12:00 pm
• David Stevenson, Ph.D.
  • Harvard Medical School
• Judith Peres, LCSW-C
  • Social Work Hospice
Overview of Session

• Brief History of End of Life Care in the U.S.
• Role of Advance Care Planning
• Intersection of Hospice & Nursing Homes
• Current Hospice Issues
End of Life Care (3)
Dying in the United States

- 1900 – life expectancy, 46 years
- People died quickly
- Medical therapies focused on caring & comfort
- People cared for the dying @ home
Dying in the United States

- Death is unavoidable

2.5 million people die each year

83% are Medicare Beneficiaries
• Origins of Palliative Care

Hospice Movement,
Dame Cicely Saunders

Elizabeth Kubler-Ross
Right to Die

- Karen Ann Quinlin - 1985
- Nancy Cruzan - 1990
- Terri Schiavo - 2005
Original Contributions

A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)

The SUPPORT Principal Investigators
**Good Death** – free from avoidable distress and suffering for patients, families, and caregivers, in accord with patients’ and families’ wishes; and consistent with clinical, cultural & ethical standards

**Bad death** – needless suffering, disregard for patient or family wishes or values and a sense among participants that norms of decency have been offended
Advance Directives

Patient Self-Determination Act (PSDA) 1990

- Requires all health care facilities receiving Medicare or Medicaid funding to inform patients of their right to refuse medical treatment and to sign advance directives.
Palliative Care

- Comprehensive management of physical, social, spiritual and existential needs of patients
- Objectives: to relieve symptoms and to improve the quality of life for patients \([\text{with chronic?}]\) as well as terminal illnesses
- Interdisciplinary Team Care
Goals of Palliative Care

• Integration of the experience of life’s end:
  – Attending to suffering in all domains:
    • Biological and Physical
    • Psychological and Emotional
    • Social and Interpersonal
    • Spiritual and Religious
    • Intellectual and Professional
  – Reviewing one’s life narrative
  – Focusing on meaning
Goals of Palliative Care

• Maintaining hope:
  – A confident expectation that good will come to one in the future

• Preserving dignity:
  – Value, esteem, lovability

• Healing vs. cure:
  – It is possible to die healed
  – Wholeness vs. Eradication of disease
Trends & Problems

• Chronic Care?
• Palliative Care (Palliative Medicine)?
  – A part of mainstream medicine? A specialty?
  – More academic, research oriented? At the expense of focus on patients and families?
  – Too afraid of being identified with care for the dying?
• Hospice?
  – A movement or a reimbursement mechanism?
  – Medical counterculture adopted by the mainstream?
  – Too exclusively focused on dying?

• Long-term Care (Support & Services)?
Medicare & Medicaid

From a public policy perspective, a tangle of coverage, financing and oversight rules govern how beneficiaries receive “palliative” care.
Policy Barriers

• Medicare
  – Coverage and payment for palliative care, complex and poorly understood.
  – Coverage dependent on whether an illness is temporary or permanent.
  – Medical necessity criteria support payment for services as long as the patient is improving.
  – For palliative care -- goal is not improvement, but comfort or slowing of disease progression.
Medicare

- Covers palliative care indirectly in most providers; explicitly through hospice:
  - Hospitals – Emerging palliative care programs… not fit Medicare coverage & payment policies (63% hospitals provide palliative care, AHA, 2009 survey)
  - SNFs – coverage & payment not intended for chronic, LTC. SNF Part A, not available once beneficiary elects hospice
End-of-Life Care

Medicare Hospice Benefit, TEFRA ’82

- Certified Hospice Services:
  - Nursing Care; Therapies (PT, OT, SP); Medical Social Services; Medical supplies, including drugs; Physician services; Counseling; Short-term inpatient & respite care; Bereavement counseling for family members
- 6 Month prognosis
- Two benefit periods of 90 days each, unlimited 60 day periods (*no actual limit*)
- Beneficiary retains coverage for acute incidents not related to terminal illness
HOSPICE

• All Medicare payment related to terminal illness – flow through hospice
• Hospices responsible for management of all services – whether provided directly or under arrangement
• New Conditions of Participation
• Growth in For-Profit Hospice
• Medicare Spending on Hospice, 2010 was $13 billion
• Spending for each beneficiary receiving hospice: $8,405 (CMS Actuary) ...check
• Total number of Medicare hospice patients: 1.1 million
• 44% of decedents in 2010
Medicaid

- Hidden source of funding for EOL care through LTC services
- 9 Million “dual eligibles”
- 66% of spending for dual eligibles for LTC services
- Hospice
  - Optional Benefit
  - Based on Medicare requirements
  - States pay 95% of NFs “room & board” rate to the hospice for Medicaid residents
David Stevenson
617-432-3905  stevenson@hcp.med.harvard.edu

Judith Peres
301-951-3707  judyperes@aol.com