Everything You Wanted to Know About Hospice
but were afraid to ask
A primer for hospitalists and emergency medicine physicians

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Why the need to understand hospice
- Patients with life limiting conditions all too frequently present to the hospital as death nears
- Factors associated with increased hospital use:
  - Uncontrollable symptoms
  - Inadequate social supports
  - Poor communication
  - Regional variables
- MDs need to help patients negotiate the balance between quantity and quality of life

Negotiating the balance
- Understand:
  - Dying trajectories
  - Symptom management of the dying patient
  - Bioethical framework that guides EOL decision making
  - Communication strategies helpful in determining goals of care
- Educate yourself about the Medicare Hospice Benefit
What do patients know about hospice?

- More than 90% have heard of hospice and more than 75% would consider using it
- More than 2/3 learned about hospice from someone who used it
- Less than 40% know that Medicare and Medicaid pay for hospice services
- More than 80% would want to use hospice in their own home

2004 AARP and Mass Commission on End of Life Survey

Hospice is...

- A philosophy of care and a therapeutic model
  - Focus is on patients with any progressive incurable illnesses and their families
  - Mission is to provide care that supports quality of life and reduces suffering throughout progressive illness, at the end of life, and during bereavement

Hospice is ...

- Interdisciplinary, comprehensive and continuous management of
  - Physical symptoms
  - Psychosocial concerns
  - Spiritual distress
  - Caregiver burden
  - Practical needs in the home
### Hospice is …
- A health care system in the United States
- Not a place, but a home care program with access to beds supported by a federal benefit (Medicare and Medicaid)
- Package of services
- Managed Care system with capitated reimbursements
- System to provide palliative care for patients with advanced illness and their families

### The Hospice Benefit
- 1979 - HCFA approves demonstration projects at 26 hospices nationally to evaluate cost-effectiveness and establish standards for services
- 1982 - Congress approves creation of a Medicare hospice benefit
- 1983 - Medicare Hospice Benefit initiated under Medicare Part A

### Settings of Hospice Services
- Home
- Skilled Nursing Facilities
- Hospice Facility
- Hospital
The Hospice Benefit

- Reimburses at no cost to the patient if related to the terminal diagnosis/prognosis
  - Professional services of the multi-disciplinary team
  - Nurse, social work, pastoral care
  - Medical oversight by hospice medical director
  - Home health aides, volunteers
  - All tests and treatments, as related to the terminal prognosis
  - All medications, as related to the terminal prognosis
  - Durable medical equipment and supplies

Physician Services

- Hospice Medical Director
  - May perform hospice eligibility consultations
  - May become physician of record if requested by referring MD
  - Available for consultation for pain and symptom management
  - Works with the physician of record to ensure that the Hospice plan of care is consistent with the patient and family’s goals of care, is medically appropriate, and within the regulations that govern hospice

- Attending Physician
  - Collaborates primarily with the hospice team nurse to implement an agreed upon plan of care
  - If not associated with the hospice program via employment or contract, bill Medicare Part B in usual fashion
  - Should not order tests, services or consultations without discussion with the hospice team

Types of Services Not Covered by Hospice

- Extensive evaluations not consistent with hospice approach that focuses on comfort, support and symptom management
- Disease modifying treatment that changes the prognosis or “curative intent”
- Continuous nursing care
- Nursing home room and board
The Hospice Benefit

- **Levels of Care**
  - Routine level of care
  - Access to inpatient level of care for acute problems
  - Access to period of continuous home care
  - Access to inpatient stay for family respite
  - Bereavement services for 13 months after the death at no cost

- **Routine Home Care**
  - Hospice care is delivered wherever the patient resides: home, SNF, assisted living, group home
  - Hospice does not cover the cost of the residence (e.g., a hospice patient in a nursing home is responsible for the room and board charge)

- **Continuous Care**
  - Provided for patient at home during a "period of crisis" that might otherwise lead to inpatient care
  - Hospice provides a minimum of 8 hours/day during a 24 hour period, not necessarily continuous
  - Nursing care must comprise 51% of the care, either RN or LPN
  - HHA may supplement nursing care
The Hospice Benefit

- Respite
  - When caregivers require a break from caregiving responsibilities
  - Must be provided in a contracted facility
  - Can be provided for a maximum of 5 days per benefit period

The Hospice Benefit

- General Inpatient Level of Care
  - For control of acute pain or other symptoms that cannot be adequately managed in the patient's home
  - Short-term care provided in a contracted facility
  - Hospice continues to manage the plan of care
  - GIP care may be for symptoms of imminent death or when there is a breakdown of the family caregiver support system if there is an intensity of care directed towards symptom management that cannot be managed in another setting.
  - Custodial care only does not qualify the patient for general inpatient care.

The Hospice Benefit

- Eligibility
  - Patient elects to focus on symptom management over curative goals
  - Patient enrolls in Medicare-certified hospice program under Medicare Part A
  - Patient's personal physician and hospice medical director certify that in their judgment, given the usual course of the disease, the patient has a life expectancy of six months or less
The Hospice Benefit

Based on the physician’s best judgment...
regarding the normal course of the individual’s illness

CMS recognizes that making medical prognosis of life expectancy is not always an exact science. Thus, physicians need not be concerned. There is no risk to a physician about certifying an individual for hospice care that he or she believes to be terminally ill”

CMS. Hospice Care Enhances Dignity and Peace As Life Nears Its End.

Medicare Coverage of Other Conditions

- Medicare continues to cover care and treatment for conditions other than the terminal illness
  - Example: 68 year-old woman with metastatic breast cancer and CHF goes to the emergency room in pulmonary edema
- Medicare Hospice benefit covers hospice services for breast cancer
- Medicare A covers hospital care for CHF
- Primary care physician and consulting physicians bill under Medicare B
Open Access Hospice

- Provides access to high-cost treatments and even life prolonging therapies to dying patients who would otherwise benefit from hospice services
- Up to the individual hospice program
- Examples:
  - Parenteral fluids
  - Enteral feedings
  - TPN
  - Transfusions
  - Radiation therapy
  - Chemotherapy
  - Antibiotics

The Hospice Benefit

- Patient eligibility must be recertified every 2 – 3 months by the primary physician and the hospice medical director
- Program can be continued as long as diagnosis and 6 month prognosis exist
- Patient can revoke the benefit at any time and return to prior system of care

- Patient becomes ineligible
  - Remission
  - Significant improve that alters prognosis
  - No penalty for discharge
  - Patient may be readmitted if becomes eligible due to declining health

- Patient elects discharge
  - Patient may choose to seek disease modifying therapy not provided by hospice
Hospice versus Home Care

- Hospice does not require patients to be homebound
- Hospice does not require a skilled need
- Interdisciplinary model of care
- Bereavement services
- Hospice covers pharmacy and DME costs related to the diagnosis

Hospice Myths

- Hospice is for patients close to dying
  - Eligibility is a prognosis of “six months if the disease runs its course”
  - Pitfalls of prognostication
- Hospice places a limit on stays
- Hastens death
- Once in hospice there is no turning back
- Only cancer patients are eligible for hospice
  - Top 5 non-cancer diagnoses: end-stage heart disease, dementia, lung disease, end-stage kidney disease, and end-stage liver disease

Hospice Myths

- Hospice is only for people who accept they are dying.
  - Patients and families often struggle to come to terms with their limited life expectancies. Hospice can help them address their fears, feelings and concerns and help them redefine hope within the context of their disease and personal lifestyles
- The patient must have a “Do Not Resuscitate” order to be eligible.
- The risks and benefits of different treatment options, including "DNR", is an ongoing discussion that may happen within the context of hospice care.
Hospice Myths

- Hospice requires that the patient have a 24 hour responsible caregiver.
- While family members are usually trained to care for their loved ones at home with the support of hospice, there are many cases where this may not be possible.
- Hospice pays for hospice residence or nursing home costs
  - Only if the patient is admitted under the GIP level of care benefit
  - Routine level of care – room and board the responsibility of patient and family
- Hospice provides 24 hour nursing care in the home

Hospice Guidelines

- Know there are guidelines for eligibility (Local Care Determinants or LCDs)
- "Would I be surprised?" question
- Ask for a consultation

Local Care Determinant Guidelines

- What questions might someone have before admission?
  - Are there ways to help someone who is not a resident?
  - Are there ways to help someone who is a resident?
  - Are there ways to help someone who is a non-resident?
  - Are there ways to help someone who is a resident and has a paid caregiver?
  - Are there ways to help someone who is a resident and has a paid caregiver and is not a resident?
  - Are there ways to help someone who is a resident and has a paid caregiver and is a resident?
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Barriers to Hospice Access
- Difficult Conversations
- Cultural Issues
- Family/Caregiver Support
- Financial Considerations: high cost drugs and treatments

The Hospice Patient in the ER
- A lack of a DNR or transfer to the ED does not necessarily terminate hospice services
- Hospice patients go to the ED when:
  - "learned" behavior in a crisis
  - Crisis: physical, spiritual, psychosocial
  - Conflict in patient or family around goals of care
  - disagree with comfort approach
  - difficulty accepting natural decline associated with terminal illness
  - Request care directed at prolonging life that cannot be provided by the hospice
  - Malfunction/loss of support device
  - Dissatisfied with hospice service or care model

The Hospice Patient in the ER
- Notify Hospice
- Determine trigger for ED visit
- If deterioration is imminent:
  - Identify surrogate, rapid GOC discussion, recommendations
- If patient is actively dying:
  - Limit laboratory tests/diagnostics
  - Therapeutic interventions should be based on goals of care rather than protocols (e.g. antibiotics in CAP)
- Disposition
Making a Referral from the Hospital

- Assess Eligibility
- Assess whether patient/surrogate goals are consistent with hospice philosophy
- Discuss disposition with primary physician
- Introduce hospice as POC
- Make referral. Anticipate questions regarding caregiver, equipment, medications, code status
- Ensure understanding and secure plan

Discussing transition to hospice

- Involve family members in discussion
- Explore patient and family goals
- Provide information about hospice care
- Explore concerns about hospice
  - Hospice myths