Objectives

The lecture attendee will:
- Realize the need to address end of life care
- Understand the differences and spectrums of end of life care
- Be able to integrate this knowledge to better care for their patients at the end of life
Palliative Care - Overview

Palliative care is a medical specialty/team that cares for people with advanced, even terminal, illness who choose to continue active therapies and management that may otherwise prolong life

Some hospice agencies provide palliative care

- Most, however, do not

Any and all care and treatment can be provided, tailored to the needs and desires of the patient

Hospice Care - Overview

Hospice addresses the patient’s physical, emotional, social and spiritual needs for those who choose to forgo palliative care

- Tailored towards the patient's wishes by a multidisciplinary team

Address family emotional, social and spiritual needs

- Some for up to a year after their loved one passes
- Most about 6 months afterwards

Can be done in any setting
- Home, LTC, Hospice Homes

Criteria must be met
End of Life - Coverage

Palliative care is currently NOT covered
Hospice care is covered 100% by Medicare Part A
Most medicaid, VA and private will cover as well
Consults of either service is generally free
Allows the service to sit down with the patient and family to go over everything they offer and answer all the financial and difficult questions

Palliative Performance Scale (PPS)

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>No evidence of disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Some evidence of disease</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable to do any activity</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50%</td>
<td>Mainly Sit/Lie</td>
<td>Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40%</td>
<td>Mainly in Bed</td>
<td>Extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Totally Bed Bound</td>
<td>Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Extensive disease</td>
<td>Total Care</td>
<td>Minimal to sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Extensive disease</td>
<td>Total Care</td>
<td>Mouth care only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Functional Assessment Scale (FAST)

1 - No difficulty either subjectively or objectively.

2 - Complains of forgetting location of objects. Subjective work difficulties.

3 - Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.

4 - Decreased ability to perform complex task, (Bills, dinner)

5 - Requires assistance in choosing proper clothing to wear for the day, season or occasion

6 Occasionally or more frequently over the past weeks. * for the following
   Improperly putting on clothes without assistance or cueing
   Unable to bathe properly (not able to choose proper water temp)
   Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue)
   Urinary incontinence
   Fecal incontinence
Functional Assessment Scale (FAST)

7

Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview.
Speaker ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview
Ambulatory ability is lost (cannot walk without personal assistance.)
Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.)
Loss of ability to smile.
Loss of ability to hold up head independently.


Hospice Criteria

GENERAL (NON-SPECIFIC) TERMINAL ILLNESS
1. Terminal condition cannot be attributed to a single specific illness.
   And
2. Rapid decline over past 3-6months Evidenced by: Progression of disease evidenced by sx, signs & test results Decline in PPS to ≤ 50%
   ■ Involuntary weight loss >10% and/or Albumin <2.5 (helpful)

ADULT FAILURE TO THRIVE
PPS < 50%
BMI < 22
Refusing enteral or parenteral nutrition support or has not responded to such nutritional support, despite adequate caloric intake
Hospice Criteria

CANCER

Patient meets ALL of the following:

- Clinical findings of malignancy with widespread, aggressive or progressive disease as evidenced by increasing sx, worsening lab values and/or evidence of metastatic disease
- Palliative performance Scale (PPS) ≤ 70%
- Refuses further life-prolonging therapy OR continues to decline in spite of definitive therapy

Supporting documentation includes:

- Hypercalcemia > 12
- Cachexia or weight loss of 5% in past 3 months
- Recurrent disease after surgery/radiation/chemotherapy
- Signs and sx of advanced disease (e.g. nausea, requirement for transfusions, malignant ascites or pleural effusion, etc.)

DEMENTIA

The patient has both:

- Stage 7C or beyond according to the FAST Scale
- One or more within 12 months:
  - Aspiration pneumonia
  - Pyelonephritis
  - Septicemia
  - Multiple pressure ulcers (stage 3-4)
  - Recurrent Fever
  - Other significant condition that suggests a limited prognosis
  - Inability to maintain sufficient fluid and calorie intake in the past 6 months (10% weight loss or albumin < 2.5 gm/dl)
**Hospice Criteria**

**HEART DISEASE**

The patient has 1 and either 2 or 3

- **1** - CHF with NYHA Class IV sx and both:
  - Significant sx at rest
  - Inability to carry out even minimal physical activity without dyspnea or angina

- **2** - Patient is optimally treated (ie diuretics, vasodilators, ACEI, or hydralazine and nitrates)
  - The patient has angina pectoris at rest, resistant to standard nitrate therapy, and is either not a candidate for/or has declined invasive procedures.

Supporting documentation includes:

- EF \( \leq \) 20%, Treatment resistant symptomatic dysrhythmias
- h/o cardiac related syncope, CVA 2/2 cardiac embolism
- H/o cardiac resuscitation, concomitant HIV disease

**HIV/AIDS**

The patient has either 1A or 1B and 2 and 3

1A. CD4+ < 25 cells/mcL OR 1B. Viral load > 100,000 AND
2. At least one (1) : CNS lymphoma, untreated or refractory wasting (loss of > 33% lean body mass), (MAC) bacteremia, Progressive multifocal leukoencephalopathy Systemic lymphoma , visceral KS, Renal failure no HD, Cryptosporidium infection, Refractory toxoplasmosis AND
3. PPS of < 50%
Hospice Criteria

LIVER DISEASE
The patient has both 1 and 2.

1. End stage liver disease as demonstrated by A or B, & C
   - A. PT> 5 sec OR
   - B. INR > 1.5 AND
   - C. Serum albumin <2.5 gm / dl AND

2. One or more of the following conditions:
   - Refractory Ascites, h/o spontaneous bacterial peritonitis,
   - Hepatorenal syndrome , refractory hepatic encephalopathy,
   - h/o recurrent variceal bleeding

Supporting Documents includes: Progressive malnutrition, Muscle wasting with dec. strength. Ongoing alcoholism (> 80 gm ethanol/day),
Hepatocellular CA HBsAg positive, Hep. C refractory to treatment

PULMONARY DISEASE
The patient has all of the following:

- Disabling dyspnea at rest, little of no response to bronchodilators
- Decreased functional capacity (e.g. bed to chair existence, fatigue and cough) AND
- Progression of disease as evidenced by a recent h/o increasing office, home, or ED visits and/or hospitalizations for pulmonary infection and/or respiratory failure. AND
- Documentation within the past 3 months ≥1: Hypoxemia at rest on room air (pO2 < 55 mmHg by ABG) or oxygen saturation < 88% Hypercapnia evidenced by pCO2 > 50 mmHg
Hospice Criteria

RENAL FAILURE

The patient has all of the following:

- The pt is not seeking dialysis or renal transplant AND
- Creatinine clearance* is < 10 cc/min (<15 for diabetics)
- AND
- Serum creatinine > 8.0 mg/dl (> 6.0 mg/dl for diabetics)

- Supporting documentation for chronic renal failure includes: Uremia, Oliguria (urine output < 400 cc in 24 hours), Intractable hyperkalemia (> 7.0),

Why be Proactive?

Approximately half will die within 3 weeks and about one-third of patients die within 1 week

- This is not acceptable

In fact there is a growing trend of hospice agencies reporting deaths within 2-4 days of hospice admission

Most people don’t know Palliative options exist; Feel there is only an “all or none” philosophy in medicine

Cancer is the most readily referred among Primary Care Physician

- Journal of Palliative Medicine 2014
Hospice - Myths

“Hospice is a death sentence”
Quite the contrary
NEJM 2010 study – “With earlier referral to a hospice program, patients may receive care that results in better management of symptoms, leading to stabilization of their condition and prolonged survival”1

- Helping your patients make these decisions and know their options means taking action
- Action leads to an open forum so the patient can feel better and may ultimately become more stable!

Hospice - Myths

Hospice is a “location”
Actually more important to correct than you’d think
- People will forgo discussing hospice because they believe they’d “have to go somewhere”
- Hospice can be done in any setting which the patient and family can fully choose
Hospice - Myths

“I have to stop all my medications”
Most medications that can help the patient in any capacity (symptom control/behavioral etc) will be continued while on hospice
In general, if the therapy is palliative, hospice will allow the procedure/medication

Identifying patients

Frequent
  ER Trips
  Falls
Continued decline
Disease Progression
New dependencies
Starting the Conversation

Realize that if the criteria is met, this will be MUCH easier than you think

They will likely be much more ready for the discussion that you will be to give it
You aren’t signing a death certificate, you are having a serious conversation about your thoughts and findings and trying to get an idea of their REAL mindset and values
If you don’t want to do it you should at least refer to Palliative

Conversation Timing

Goals of care should be discussed early and often and include all parties involved

Ideally at every clinical encounter involving decisions affecting care
Prior planning in the disease trajectory guides decision making in a life threatening crisis
Conversations should not only center around end of life care, but also emphasize how the patient wishes to spend their remaining time
Treatment goals should ideally be discussed separately from the delivery of life-altering news
Establishing Goals

Ensuring care plans are clearly defined, understood and honored by clinicians and family members are key in appropriate medical care.

Family members most common complaint is infrequent communication with the Physician.

Communication between the treatment team and patient are vital.

Wishes and values of the patient should be at the foundation of care.

Discussing Goals

Defining goals – should include more than just code status, encompassing:

- Intensity of treatment

- Advanced care planning

- “Best/worst case scenarios”
Hospice Care in the Home

- May follow home-based palliative care for patients who are not benefitting from disease-directed interventions
- Hospice care is available at home provided by an interdisciplinary team
- Bridge programs may be incorporated
  - For patients who do not meet hospice eligibility criteria at time of referral. May offer family support as well

Nursing Home Palliative Care

- Caring for patients in Nursing homes is challenging due to comorbidities and need for constant care
- Structured interviews done at intake and subsequent intervals are necessary for assessing decline in function
- Cleanliness and hygiene (skin, oral care, management of incontinence) are vital
- Prioritizing goals with family (prolonging life vs maximizing comfort) should be addressed
Palliative care for Homeless Persons

Special needs with limited access to health care system make palliative care in the homeless population difficult

Medical respite programs can offer relief for should be investigated for homeless individuals

Homeless patients are at a greater risk of receiving end of life care inconsistent with their wishes, especially if they lack decisional capacity. These Patients especially should be encouraged to complete Advanced Directives (ADs)

Last Hours/Days of Life

Patients enrolled hospice programs are less likely to die in the hospital and allow for dying to happen at a preferred location

Care should also be directed towards the family as the patient enters the actively dying phase to offer support

Family should be informed of the natural dying process (changes in respiratory rate, changes in level of consciousness, secretions) can help family prepare for the final moments with their loved ones

Cardiopulmonary resuscitation may be expected by patients and families and should therefore be addressed through proactive communication, despite the potentially harmful treatment
Pain in the Dying Individual

Pain is widespread among dying individuals, regardless of the illness/disease.
Members of the care team should be vigilant in identifying suffering patients and act quickly to remediate the situation.
Pain associated with advanced illness can be controlled in most patients up to end of life.

Treating Pain in the Last Weeks of Life

Pharmacologic
Opioids (Morphine, Fentanyl, Methadone)
- Levorphanol – long half-life, acts on both mu and delta opioid receptors. Option for patients with advanced illness who may not tolerate other drugs
Acetaminophen
NSAIDs
Treating Pain in the Last Weeks of Life

Adjuvant analgesics

Neuropathic pain
- (Gabapentin, Glucocorticoids, SSRIs)

Bone pain
- (Glucocorticoids, NSAIDS)
  - Recent trials have revealed promising results in treating bone pain with bisphosphonates such as ibandronate

Psychological approaches

Guided Imagery – use of words and music to evoke positive feelings and outlooks
Meditation
Music Therapy
Relaxation Therapy
Treating Pain in the Last Weeks of Life

Nonpharmacologic treatment options
- Transcutaneous Electrical Nerve Stimulation (TENS)
- Therapeutic exercise
- Particular nerve blocks
- Splints
- Massages

Credits


Quality end-of-life care: patients’ perspectives. Toronto Hospital and the Department of Medicine, Joint Centre for Bioethics, University of Toronto, Ontario, Canada. peter.singer@utoronto.ca