End of Life Care

Palliative and Hospice:
A Better Understanding

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LAKE ERIE INTEGRATED GERIATRIC HEALTH TEAM

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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

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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

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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**

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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

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Palliative Performance Scale (PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

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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

Functional Assessment Scale (FAST)

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)

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- 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.
- Speech 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.2

*Scored primarily on information obtained from a knowledgeable informant.

Psychopharmacology Bulletin, 1988 24:653-659.

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Hospice Criteria

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- 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

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Hospice Criteria

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- 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.)

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Hospice Criteria

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- 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)

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Hospice Criteria

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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 ≤ 20%, Treatment resistant symptomatic dysrythmias
- h/o cardiac related syncope, CVA 2/2 cardiac embolism
- H/o cardiac resuscitation, concomitant HIV disease

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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%

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Hospice Criteria

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- 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

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Hospice Criteria

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- 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 (p02 < 55 mmHg by ABG) or oxygen saturation < 88% Hypercapnia evidenced by pC02 > 50 mmHg

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Hospice Criteria

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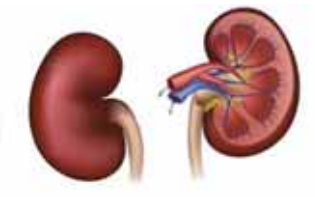

RENAL FAILURE

- 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),

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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

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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

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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

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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

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Discussing Goals

- Defining goals – should include more than just code status, encompassing:
  - Intensity of treatment
  - Advanced care planning
  - "Best/worst case scenarios"

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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

Treating Pain in the Last Weeks of Life

- 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

1 - J Temel etal, “Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer”, NEJM, 2010.

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8:1Quality end-of-life care: patients' perspectives.
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