Palliative Care
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Definition of Palliative Care
Palliative Care seeks to prevent, relieve, reduce or soothe the symptoms of a patient whose disease is not responsive to curative treatment.

WORLD HEALTH ORGANIZATION
Case #1

76 y/o male admitted to step down unit with exacerbation COPD. Just discharged 5 days prior after hospitalization for similar event. Has had 5 hospital admissions for pulmonary disease events in last 4 months. Patient has been functionally declining for about one year and short of breath with activities of daily living for 6-8 months. O2 and steroid dependent

Case #1 cont . . .

1) Is patient appropriate for palliative care consult?
2) Would patient have been appropriate 5 admits ago?
3) What could palliative care consultant add to patient’s care?
4) Could palliative care consultant add something no matter who is caring for patient?
5) What is patient’s prognosis?
What is Palliative Care?

- A team approach to care with emphasis on quality of life and symptom management for patients with life-limiting illnesses simultaneously with all other appropriate forms of treatment.

Palliative Care ‘Imperative’

<table>
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<th>Year</th>
<th>Population age 65+</th>
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<tr>
<td>1997</td>
<td>17%</td>
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<tr>
<td>2010</td>
<td>23%</td>
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<td>2015</td>
<td>33%</td>
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US Dept of Health and Human Services
When is Palliative Care Appropriate?

- Anytime during course of patient’s illness
- Often when patients feel:
  - TOO SICK TO LIVE, NOT SICK ENOUGH TO DIE
Why Palliative Care?

- INSTITUTE OF MEDICINE - identified a need for an increased focus on palliation as a goal of treatment and noted that this objective is "undermined by a system that focuses on either active treatment or on palliative or hospice care, and does not readily allow these approaches to be integrated"

Target population for better "End of Life Care"

- 1. Very sick (disabled, dependent, debilitated)
- 2. Generally getting worse
- 3. Will die, most likely from progression of illness
- (near neighbors) chronic conditions, Disabilities; Aging; Earlier phase of fatal illnesses; Statistically likely to die, but not yet sick
Severity of Illness, not Prognosis

- Prognosis often uncertain, right up to the end of life
- Severity of patient condition dictates needs
- Most patients need both disease-modifying treatments and help to live well with disease

Sudden death, unexpected cause

- < 10%, MI, accident, etc
Steady decline, short terminal phase

Slow decline, periodic crises, sudden death
Multivariable Models for Very Sick Patients Cannot Predict Time of Death Precisely

Median of Predictions estimated from Data on Days before Death

Kass, L.R. JAMA 1980:244:1947

- “If medicine takes aim at death prevention rather than at health and relief of suffering, if it regards every death as premature, as a failure of today’s medicine—but avoidable by tomorrow’s—then it is tacitly asserting that its true goal is bodily immortality...Physicians should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death must come, that health is a mortal good and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine.
Case #2

- 44 y/o female with breast cancer for 5 years, admitted with brain mets newly diagnosed after new onset seizure at home. Has lost function of right arm and has some slurred speech despite treatment. Now in Rehab unit. Husband struggling because patients 9 y/o does not want mother back home for fear of recurrent seizure, yet patient wants to go home.

Case #2 cont . . .

1) Is patient appropriate for palliative care consult?
2) What could palliative care consultant add to patient’s care?
3) Could palliative care consultant add something no matter who is caring for patient?
4) What is patient’s prognosis?
Essential Components of Palliative Care

- Symptom Relief
- Teamwork & Partnership
- Life-Prolonging Treatment
- Openness
- Psychosocial Support
- Honesty

Hospice vs. Palliative Care

- **HOSPICE**
  - 6 months or less
  - defined by Medicare benefit
  - forego live prolonging Rx
  - levels of care
  - goals same

Twycross RG. *Introducing Palliative Care*. 1996
Hospice vs. Palliative Care

- PALLIATIVE CARE
- Traditional Medicare benefit
- anytime during illness
- no need to forego life-prolonging Rx
- goals same

Comfort Care

- Different for each person
- Really just a plan of care, not a service
- Usually means less aggressive approach to care
- What meds to give can be difficult to assess
Where-Palliative Care?
Site of Death: Time Trends


National data on the experience of dying in 5 tertiary care teaching hospitals

- The SUPPORT Study
- Controlled trial to improve care of seriously ill patients
- Multicenter study funded by RWJ
- 9000 patients with life threatening illness, 50% died within 6 months of entry

- JAMA 1995;274:1591-98
SUPPORT: Phase I Observational Study

- Determine objective measures of quality of death:
  - Presence and timing of written DNR
  - MD awareness of DNR preferences
  - Number of 'undesirable days
  - Pain levels
  - Costs of Care

SUPPORT: Phase I Results

- 46% of DNR orders written within 2 days of death
- Of patients preferring DNR, <50% of the doctors were aware of their wishes
- 38% of those who died spent > 10 days in ICU
- Half of patients had moderate-severe pain>50% of last 3 days of life
Pain Data From SUPPORT

- % of 5176 patients reporting moderate to severe pain between days 8-12 of hospitalization
- colon cancer 60%
- liver failure 60%
- lung cancer 57%
- MOSF + cancer 53%
- MOSF + sepsis 52%
- COPD 44%
- CHF 43%
- Desbiens & Wu. JAGS 2000;48:S183-186

Family caregivers and the SUPPORT study JAMA 1995;272:1859

- Patient needed large amount of family caregiving: 34%
- Lost most family savings: 31%
- Lost major source of income 29%
- Major life change in family: 20%
- Other family illness from stress: 12%
- At least one of the above: 55%
TO DO WELL

- WHAT SHOULD NOT BE DONE AT ALL

Case #3

- 90 y/o female admitted last pm, brought to ED by niece as patient was having trouble swallowing, short of breath and “getting weaker”
  Work-up showed slight dehydration, patient thin and with some confusion.
Case #3 cont . . .

1) Is patient appropriate for palliative care consult?
2) What could palliative care consultant add to patient’s care?
3) Could palliative care consultant add something no matter who is caring for patient?
4) What is patient’s prognosis?

High level of burdensome interventions in hospitalized, dying patients

- Comparative study of 164 older adults with advanced metastatic cancer or end-stage dementia who died during the index hospitalization
- 47% received invasive non-palliative interventions -(multiple diagnostic tests, therapeutic interventions, artificial nutrition and hydration)
- 24% received CPR
Why Hospital-Based Palliative Care?

- Teaching hospitals are the site of training for most clinicians
- Acknowledged deficits in skills/knowledge and attitudinal barriers abound
- Medical school and residency curricula offer little to no teaching in palliative care
  - Meier, Morrison & Cassel

Hospital Stay with Serious Illness

- 98% of Medicare decedents spent at least some time in a hospital in the year before death
- 15-55% if decedents had at least one stay in an ICU in the 6 months before death
- 40% of MEDICARE payments in 1988 in last 30 days before death
COMMUNICATION

- IT’S HARD TO BE TOLD, BUT IT’S HARD TO TELL TOO.”
  - Dr. Cicely Saunders

Advanced Cancer: family conferences (N=50) questions (miller, pall med 1991)

- extent of disease: 72%
- life expectancy: 84%
- future complications: 50%
- treatment options: 40%
- home nursing: 40%
- pain/meds: 38%
- can family manage at home?: 36%
- chance of recovery: 32%
- diagnosis: 26%
Hospital Based Palliative Care Team

- physician, nursing, social work, pastoral care, psychiatry, pharmacist, dietician, PT, OT, administration, volunteers

The Palliative Care Consult

- TYPES OF CONSULTS - GENERAL
  - Assessment/mgmt. of physical symptoms, psychological and spiritual needs
  - Assisting patients to identify personal goals/decision making
  - Assessment of patient’s support system
  - Assessment and communication of estimated prognosis
  - Assessment of discharge plan/issues
“IF YOU CAN’T DO EVERYTHING, IT DOESN’T STOP YOU DOING SOMETHING.”
Dr. Cicely Saunders

How to Introduce Palliative Care

- “I want you to get every service available to you.”
- “I need help”
- “We need to make a plan for what happens next”
- “This is a tough time and I what to get you some help”
What do patients want?

- Patient Preferences Regarding CPR Influence of Survival Probability

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<tr>
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<th>Acute Illness</th>
<th>Chronic Illness</th>
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<tr>
<td>Estimated probability of surviving after CPR</td>
<td>26% +/- 22</td>
<td>15% +/- 16</td>
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<td>Preferred CPR before knowing probability</td>
<td>41%</td>
<td>11%</td>
</tr>
<tr>
<td>Preferred CPR after learning survival probability</td>
<td>22%</td>
<td>5%</td>
</tr>
<tr>
<td>&gt; 85 years old</td>
<td>6%</td>
<td>3%</td>
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- 42% would want CPR if < 50% chance of leaving hospital
- 25% would not want CPR if 100% chance of leaving hospital

Murphy et al NEJM 1994

Expression of Wishes in Response to Loss, Futility and Unrealistic Hope

- Avoid hopeful statements unless there is a reasonable chance of success.

- Statements of wishes can:
  - Acknowledge limited control over a situation by a physician
  - Express regret that more can not be done.
  - Allow clinician to enter patient’s world.
  - Result in deeper level of conversation.
  - Humanizes the medical encounter

Quill et al Ann Int Med 2001
Expression of Wishes in Response to Loss, Futility and Unrealistic Hope

- **Clinical Scenario**
  - Delivering very bad news
  - Responding to unrealistic hopes
    - From a patient or family
  - Responding to demands for aggressive treatment when prognosis is very poor
  - Responding to expressions of loss, grief, and hopelessness

- **Sample Response**
  - I wish I had better news to give you
  - I wish that were possible. It sounds like all of us would be would be a lot happier if that were so.
  - It must be very hard to come to the intensive care unit every day and see so little change. I wish medicine had the power to turn things around.
  - It sounds like a terrible loss for you. I wish it hadn’t turned out this way.


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**The Death of Ivan Ilych - Tolstoy**

- What tormented Ivan Ilych most was the deception, the lie . . . That he was not dying but was simply ill, and that he only need keep quiet and undergo treatment and then something very good would result.
What help is available?

- Social work
- Palliative Care
- Hospice Info visit
- Websites
- Booklets

“MAY YOU LIVE ALL THE DAYS OF YOUR LIFE”

W.B. YEATS