Palliative Care

Alice Foy, ARNP
Seattle VA
Palliative care

• Definitions
• Origins
• Benefits/Outcomes
• Primary vs. Specialty
• Domains
• Symptoms
• Summary
Definition of Palliative Care

Specialized medical care for people with serious illnesses… focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and family… provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.

Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Center to Advance Palliative Care 2011
Palliative care is ________:

• A philosophy of care.
• An organized, structured system for delivering care.
• Offered when a person is living with an illness that will worsen and eventually cause death.
• The central component of treatment when cure or life-prolongation is no longer possible.
Origins of palliative care

• Modern hospice, palliative care: 1940’s England, Cicely Saunders, a nurse
  – Worked at St. Luke’s Hospital, a “home for terminal care”
  – Attended medical school, then
  – 1967 established St. Christopher’s Hospice in London, the first modern hospice.
End-of-life care was lacking in the U.S.

• SUPPORT trial (1995)
  
  – 5 teaching hospitals across US, 9105 adults hosp. with one or more of 9 life-threatening diagnoses; overall 6-mo. mortality 47%

  – Phase I: observation
    • Fewer than half of physicians knew when pts. wished to avoid CPR.
    • Almost half of DNR orders written within 2 days of death.
    • More than 1/3 of patients who died spent at least 10 days in ICU.
    • Half of patients who died reported mod. to severe pain at least half the time.

  – Phase II: intervention
    • Physicians were given updated estimates of 6-mo. survival, outcomes of CPR, and functional disability.
    • Specially trained nurse had multiple contacts with pts., families, physicians, and hospital staff to elicit preferences, understand predicted outcomes, symptoms control, advance care planning, patient-physician communication.

The SUPPORT Principal Investigators. 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). JAMA 1995; 274(20): 1591-98
SUPPORT trial, cont.:  

• Outcomes:  
  – No improvement in:  
    • patient–physician communication  
    • Incidence or timing of written DNR orders  
    • Physicians’ knowledge of patients’ preferences for resuscitation  
    • ICU days on ventilator or comatose before death  
    • Pain levels  
    • Resource utilization
• We were providing aggressive care without knowing patient preferences, and not improving quality of life or symptoms.
1997 Institute of Medicine report, “Approaching Death: Improving Care at the End of Life”

- Too many people suffer needlessly at the end of life
- Failure to provide effective supportive care
- Caregivers continue practices known to be ineffective
  - Ex: misapplication of life-sustaining technologies
- Legal, organizational, and economic obstacles continue to obstruct palliative care for the dying
  - Ex: reimbursement systems that provide incentives for procedures and disincentives for supportive services
- Training of health care professionals in palliative medicine is inadequate.
  - 2006 American Council for Graduate Medical Education approved hospice and palliative medicine as a new subspecialty.
- Deficiencies in evidence-based practice concerning end-of-life issues
Dichotomous model of health care delivery:

- Early models: “Life-prolonging vs. palliative care”
  - Palliative care was
    - Equated with “end-of-life” only
    - Delivered late in course of illness
    - ICU’s, or uncontrolled symptoms
    - Interventions were too late, no longer desired
  - Driven by reimbursement system:
    - Regular Medicare covers curative therapies
    - Medicare hospice covers comfort care
3 common trajectories of late-life illness:
• Current model of palliative care:
  - Palliative care services provided earlier to have a meaningful effect on quality of life and end-of-life care
  - Provided concurrently with life-prolonging treatments
  - Hospice is still the label for terminal phase, last 6 months of life
  - Recognition that bereavement is an important part of care
Palliative care: for patients with serious illness, identifying goals of care, treating symptoms, and improving quality of life

End-of-life care: for those who have disease in terminal phase

Hospice care: end-of-life care in the last 6 months of life
# Palliative care vs. hospice: Related but distinct

<table>
<thead>
<tr>
<th></th>
<th>Palliative Care</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Initiation</strong></td>
<td>Ideally with onset of symptoms, or anywhere along disease trajectory</td>
<td>During the last 6 mos. or less of illness</td>
</tr>
<tr>
<td><strong>Life-prolonging therapy?</strong></td>
<td>May continue concurrently</td>
<td>Not allowed, per Medicare criteria</td>
</tr>
<tr>
<td><strong>Site of care delivery</strong></td>
<td>In hospitals or outpatient settings, expanding...</td>
<td>At home, or in long-term care or contracted facilities</td>
</tr>
<tr>
<td><strong>Goals of care</strong></td>
<td>• Goal-setting (cure, life prolongation, QOL, function)</td>
<td>• Inherently recognizes end-of-life</td>
</tr>
<tr>
<td></td>
<td>• Symptom management</td>
<td>• Symptom management</td>
</tr>
<tr>
<td></td>
<td>• Enhance quality of life</td>
<td>• Often assumes care of the patient from primary care during the terminal phase</td>
</tr>
<tr>
<td></td>
<td>• Maximize function</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Support primary care team before patient is terminally ill</td>
<td></td>
</tr>
<tr>
<td><strong>Interdisciplinary</strong></td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
National Consensus Project
Tenets of Palliative Care:

- Patient and family centered care.
- Comprehensive, with continuity across health settings.
- Begins early, at diagnosis of a serious or life threatening illness.
- Interdisciplinary and collaborative.
- Team members have clinical and communication expertise.
- Goal is relief of physical, psychological, emotional, and spiritual suffering of patients and families.
- Focus on quality care.
- Equitable access to palliative care services.
Goals of palliative care

• Improving quality of life
  – Comprehensive symptom management
  – Patient and family support
  – Spiritual support

• Assistance with decision-making
  – Shared decision making
  – Goals of care
  – Advance care planning

• Communication amongst all those involved in care
• Coordination across all sites of care
• Minimize invasive interventions in late stages of illness
• Staff support
Outcomes benefits

– RCT of 151 patients newly diagnosed with NSCLC
  • Intervention was monthly meetings with outpatient palliative care team
– 107 survived 12 week period of study

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>EPC + SC (n=57)</th>
<th>SC (n=47)</th>
<th>At 12 wk</th>
<th>RRR (95% CI)</th>
<th>NNT (CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression§</td>
<td>16%</td>
<td>38%</td>
<td></td>
<td>59% (19 to 80)</td>
<td>5 (3 to 19)</td>
</tr>
<tr>
<td>Anxiety§</td>
<td>25%</td>
<td>30%</td>
<td></td>
<td>18% (–54 to 56)</td>
<td>Not significant</td>
</tr>
<tr>
<td>Aggressive end-of-life care</td>
<td></td>
<td></td>
<td>(n=49)</td>
<td>(n=56)</td>
<td>At a median 5.7 mo follow-up</td>
</tr>
<tr>
<td></td>
<td>33%</td>
<td>54%</td>
<td></td>
<td>39% (4 to 62)</td>
<td>5 (3 to 56)</td>
</tr>
</tbody>
</table>

Abbreviations defined in Glossary. RRR, NNT, and CI calculated from data in article. §Hospital Anxiety and Depression Scale subscale scores > 7 out of 21. || Assessed for 105 patients who died: chemotherapy ≤ 14 d before death, no hospice care, or hospice admission ≤ 3 d before death.

Outcomes

• Better QOL on FACT-L scale (“Functional assessment of cancer therapy – lung”, possible score 0-136; study score 98.0 vs. 91.5, p = 0.03)
• Fewer depression symptoms (16 vs. 38%, p = 0.01)
• Greater documentation of resuscitation choices in medical record
• Reduced use of aggressive end-of-life care
  – By eliciting patient goals
  – Ensuring treatment plans reflected goals of care
• Longer median survival, despite less aggressive care (11.6 vs. 8.9 mos.; p = 0.02)—unanticipated finding

Figure 3. Kaplan–Meier Estimates of Survival According to Study Group.
Survival was calculated from the time of enrollment to the time of death, if it occurred during the study period, or to the time of censoring of data on December 1, 2009. Median estimates of survival were as follows: 9.8 months (95% confidence interval [CI], 7.9 to 11.7) in the entire sample (151 patients), 11.6 months (95% CI, 6.4 to 16.9) in the group assigned to early palliative care (77 patients), and 8.9 months (95% CI, 6.3 to 11.4) in the standard care group (74 patients) (P=0.02 with the use of the log-rank test). After adjustment for age, sex, and baseline Eastern Cooperative Oncology Group performance status, the group assignment remained a significant predictor of survival (hazard ratio for death in the standard care group, 1.70; 95% CI, 1.14 to 2.54; P=0.01). Tick marks indicate censoring of data.
Conclusions of study:

• Palliative care is beneficial early in the treatment of patients with serious illness.

Not just for cancer care

- COPD
- CHF
- Pulmonary hypertension
- ESRD
- Neurodegenerative disease (ALS, Huntington’s, MS)
- Critical illness in ICU’s
Not just for inpatients

• Models of palliative care delivery
  – Hospital based programs
    • Consultation services
    • Inpatient palliative care units
    • Co-management
  – Non-hospital palliative care services
    • Ambulatory palliative care visits
    • Home based
  – Hospice models
    • For patients at the end-of-life
Palliative care specialists can not assume all aspects of care

• Important for Palliative Care tools and techniques to be incorporated into basic nursing skill sets and standards of practice.

• Nurses play a crucial role in communication and symptom management in patients with advanced illness.

• Nurses should have a meaningful presence in all phases of care and planning. Attend those family meetings!!
• Primary palliative care
  – Care provided by all clinicians caring for patients with serious illness

• Specialty palliative care
  – Care provided by palliative care specialists including physicians, nurses, social workers, spiritual care providers and others
Primary palliative care

• Basic management of pain and symptoms
• Basic management of depression and anxiety
• Basic discussions about
  – Prognosis
  – Goals of treatment
  – Suffering
  – Code status

Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model.  NEJM 2013; 368(13): 1173-75
Specialty palliative care

• Management of refractory pain or other symptoms
• Management of more complex depression, anxiety, grief, and existential distress
• Assistance with conflict resolution regarding goals or methods of treatment
  – Within families
  – Between staff and families
  – Among treatment teams
• Assistance in addressing cases of near futility

Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. NEJM 2013; 368(13): 1173-75
When to seek palliative care

• A potentially life-limiting or life-threatening condition and...
  
  – Primary criteria
  
  • The “surprise question”: You would not be surprised if the patient died within 12 months.
  
  • Frequent admissions (e.g. more than 1 admission for same condition within several months)
  
  • Complex care requirement (e.g. functional dependency; complex home support for ventilator/antibiotics/feedings)
  
  • Declines in function, feeding intolerance, or unintended decline in weight (e.g. failure to thrive)

Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. Journal of Palliative Medicine 2011; 14(1): 17-22
Criteria for a palliative care assessment: at the time of admission

— Secondary criteria

• Admission from long-term care facility or medical foster home
• Elderly patient, cognitively impaired, with acute hip fracture
• Metastatic or locally advanced incurable cancer
• Chronic home oxygen use
• Out-of-hospital cardiac arrest
• Current or past hospice program enrollee
• Limited social support (e.g. family stress, chronic mental illness)
• No history of completing an advance care planning discussion/document

Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. Journal of Palliative Medicine 2011; 14(1): 17-22
What about the outpatient setting?

• Criteria for palliative care assessments are not yet available

• Primary care clinician should consider consultation for patients who have
  – poorly controlled symptoms
  – frequent visits to the emergency room
  – one or more hospital admissions in 30 days
  – a prolonged hospitalization and/or a prolonged ICU stay
  – Ask “Would you be surprised if the patient died within 12 months”
6 domains

1. Pain and other physical symptoms
2. Psychological, psychiatric, cognitive symptoms
3. Illness understanding and care preferences
   a. Personal goals, expectations
   b. Illness trajectory
   c. Risks/benefits of therapies
4. Existential and spiritual concerns
5. Social and economic resources
6. Coordination of care across settings
“PAIN RULES”

- Pain
- Anorexia
- Incontinence
- Nausea and GI (constipation, vomiting, diarrhea)
- Respiratory
- Ulcerations (skin problems)
- Level of functioning (performance scales)
- Energy (fatigue, asthenia)
- Sedation (“sleep”, “side effects”)
“Total pain” (Cicely Saunders)

• The concept which provides a defining framework for patient assessment in palliative care
• Refers to the complex mechanisms and manifestations of suffering, including its physical, emotional, socioeconomic, and spiritual components.
Oral morphine equivalents

• The “1:2:3” rule:
  o 1 mg IV MS =
  o 2 mg po oxycodone =
  o 3 mg po MS

• The “30:20:10:7.5:1.5” rule:
  o 30 mg po MS =
  o 20 mg po oxycodone =
  o 10 mg IV MS =
  o 7.5 mg po hydromorphone =
  o 1.5 mg IV hydromorphone

Example:
Pt. taking MS Contin 60 mg q12h + oxycodone 10 mg q4h prn, 5x/d. How many oral morphine equivalents?

Ans:
Morphine 60 x 2 = 120
Oxycodone 10 x 5 x (3/2) = 75
Oral morphine equivalents 195
Management of opioid side effects

• Nausea
  – Usually temporary, 3-5 days
  – Antidopaminergic antiemetics (metoclopramide, prochlorperazine)
  – Refractory—try corticosteroids, or ondansetron
  – More constant drug levels helpful—change to long-acting, topical, or shorter dose intervals

• Constipation
  – stimulant (Senna or bisacodyl), or osmotic laxative (polyethylene glycol; or mag. citrate, lactulose)
  – Stool softeners alone ineffective

• Pruritus
  – Rare; caused by histamine release
  – Switch to another opioid
  – antihistamines

• Sedation
  – Dissipates as tolerance develops
  – Dose reduction or drug rotation
Visceral pain

- Dull, colicky, poorly localized
- Caused by distention, torsion, inflammation
- Pancreatic, hepatic, renal, intestinal cancer
- Autonomic symptoms—nausea, diaphoresis
- Referred pain—liver, gallbladder -> R shoulder
- Constipation—disease, meds., immobility
- Palliative surgery to relieve obstruction
- Blockade of celiac, sympathetic or splanchnic plexuses
Neuropathic pain

- Direct pathologic changes to central or peripheral nervous system
  - Nerve root compression, encroachment of fibers on nerve plexus
  - Burning, tingling, stabbing, shooting
- Corticosteroids
  - reduce edema and pain of obstruction; improve mood/appetite/energy
  - Lyse certain tumors, enhancing analgesic effects of pain meds.
  - Effective for:
    - malignant infiltration of brachial and lumbar plexus
    - cord compression
    - headache from brain tumors
- Peripheral neuropathy
  - Opioids
  - TCA’s
  - Venlafaxine or duloxetine—for dual pain and depression
  - Gabapentin
  - Pregabalin
Bone pain

- Bone metastases
  - XRT
  - Corticosteroids
  - Bisphosphonates
  - Interventional procedures
    - Cryoablation
    - Radiofrequency ablation
Fatigue

• The most common symptom
• Underdiagnosed, undertreated
• Contributors
  – Cancer, cancer treatment, anemia, mood disorders, sleep, pain/anxiety, infections, deconditioning, cachexia, hypoxia, dehydration, polypharmacy, etc.
• Treatment—aimed at underlying causes
  – Pharm: steroid, megestrol, methylphenidate, antidepressants
Dyspnea

• Causes:
  – Cardiac or pulmonary processes
  – Debilitation
  – Wasting syndromes
  – Neurodegenerative disorders
  – Progressive, chronic disease

• Potentially treatable causes
  – Pleural effusions
  – Pneumonia
  – Severe anemia
  – Ascites

• Subjective severity correlates poorly with resp. rate, ABG, SaO2 %, use of accessory muscles
Dyspnea

• Treatment:
  – **Gold standard:** oral morphine, low dose 10-20 mg/day
  – Benzodiazepines NOT consistently useful, unless treating anxiety
  – O2: useful if hypoxemic, but otherwise no better than room air
  – Nonpharmacologic
    • Helpful: breathing training, gait aids, neuroelectrical muscle stimulation, chest wall vibration
    • Not helpful: music therapy, relaxation, fan use, counseling, psychotherapy
### Common causes of nausea and vomiting in palliative care

<table>
<thead>
<tr>
<th>Toxic/metabolic</th>
<th>Disorders of viscera</th>
<th>CNS causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drugs</td>
<td>Obstruction</td>
<td>Increased intracranial pressure</td>
</tr>
<tr>
<td>Cytotoxic chemotherapy</td>
<td>Gastric outlet</td>
<td>Malignancy</td>
</tr>
<tr>
<td>Opioids, tramadol</td>
<td>Small bowel</td>
<td>Hemorrhage</td>
</tr>
<tr>
<td>NSAIDs, aspirin</td>
<td>Biliary/pancreatic duct</td>
<td>Cranial irradiation</td>
</tr>
<tr>
<td>Digitalis</td>
<td>Constipation</td>
<td>Abscess</td>
</tr>
<tr>
<td>Iron</td>
<td><strong>Gastroparesis</strong></td>
<td><strong>Vestibular</strong></td>
</tr>
<tr>
<td>Antibiotics</td>
<td><strong>Inflammation/irritation</strong></td>
<td>Drug effects</td>
</tr>
<tr>
<td>Theophylline</td>
<td>NSAID</td>
<td>Labyrinthitis</td>
</tr>
<tr>
<td>SSRIs and bupropion</td>
<td>Chemotherapy: (direct GI effects)</td>
<td></td>
</tr>
<tr>
<td>Many other drugs</td>
<td>Radiation</td>
<td></td>
</tr>
<tr>
<td><strong>Organ failure</strong></td>
<td>Gastritis</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Liver, renal</td>
<td>Gastroenteritis</td>
<td>Anticipatory nausea and vomiting</td>
</tr>
<tr>
<td><strong>Metabolic</strong></td>
<td>Hepatitis</td>
<td></td>
</tr>
<tr>
<td>Hypercalcemia</td>
<td>Cholecystitis</td>
<td></td>
</tr>
<tr>
<td>Hyponatremia</td>
<td>Pancreatitis</td>
<td></td>
</tr>
<tr>
<td>Ketoacidosis</td>
<td><strong>Tumors of the gastrointestinal tract and thorax</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Poisoning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Substance abuse</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SSRI:** selective serotonin reuptake inhibitor.
Nausea: which treatment for which cause?

- Opioids: dopaminergic signaling (metoclopramide, prochlorperazine)
- Chemotherapy: serotonin antagonists (ondansetron)
- Increased intracranial pressure: corticosteroids
- Mechanical bowel obstruction:
  - Pharm: dexamethasone, octreotide, haloperidol
  - Non-pharm: venting gastrostomy; sleeve
- Radiation: serotonin antagonists (ondansetron)
- Motion sickness, cerebellar mets.: anticholinergic antihistamines (scopolamine, meclizine, diphenhydramine)
- If obstruction ruled out: metoclopramide + dexamethasone; glycopyrrolate (antichol.)
Agitation, distress

• Reversible causes: pain, urinary retention, fecal impaction
• Delirium: diagnosis of exclusion
• Manifestations of distress: non-specific
  – Hyperactivity vs. apathy
  – Moaning or grunting
  – Irregular breathing and tracheal secretions (“death rattle”)
• Very distressing for families; clinician plays key role in educating re. signs of death and dying
• Prophylactic anticholinergic (scopolamine) during active dying reduce tracheal secretions
Delirium

• Definition: acute change in mental status
• R/O treatable causes: meds., pain, urinary obstruction, bowel impaction, sensory deprivation
• Treatment:
  – Small doses haloperidol; chlorpromazine (10-25 mg po or sq; more sedating)
  – Avoid benzos: paradoxical worsening
  – Non-pharm: re-orienting; bedside sitter
Depression

• Transiently depressed mood normal in serious, life-threatening illness

• Symptoms persisting weeks and meeting diagnostic criteria for depression are not “normal”, and should be treated
  – Grief vs. depression

• Pharmacologic treatments:
  – SSRI’s
  – Methylphenidate
  – Mirtazapine (depression w/ insomnia, anorexia)
  – TCA’s, duloxetine, venlafaxine (w/ neuropathic pain)
Anorexia

• Common in cancer and chronic disease
• Eating/enjoying food essential in social interactions
• Distressing to patients and families
  – “Giving up!”, guilt for caregivers and patients
• Educating patients and caregivers
• Appetite stimulants if death not imminent
  – Progestins
    • megestrol 400-800 mg po qd
    • Medroxyprogesterone 500 mg po bid
    • Side effects: thromboembolic, hyperglycemia, adrenal suppression, vaginal bleeding
  – Corticosteroids
    • Dexamethasone 2-4 mg po bid
  – No impact on mortality, +/- QOL
Spiritual and psychological distress

• “Are spirituality or religion important in your life?”
• “What brings purpose to your life?”
• “This sort of illness often raises significant questions...How are you dealing with this?”
• HOPE, FICA, SPIRIT
• Consult your Chaplain!!!
• “Hoping for a Miracle”
Factors contributing to effective coping

- Good communication
- Trust among patient, family, and clinical team
- Opportunities to share fears and concerns
- Meticulous attention to physical symptoms
- Attention to psychological and spiritual concerns
Advance care planning

- Living Will
- Durable power of attorney for health care
- POLST
- Life sustaining treatments
- Medical devices (pacemakers, defibrillators)
- Dialysis termination
- Ethics consultation when indicated
Summary: Evidence based interventions

1. Regularly assess patients for:
   - Pain
   - Dyspnea
   - Depression

2. Use therapies of proven effectiveness to manage pain
   - NSAID’s
   - Opioids
   - Bisphosphonates (bone pain in breast ca, myeloma)

3. Use therapies of proven effectiveness to manage dyspnea
   - Opioids
   - O2 for hypoxemia
   - Beta-agonists (COPD)

4. Use therapies of proven effectiveness to manage depression
   - SSRI’s, TCA’s
   - Psychosocial intervention

5. Ensure advance care planning occurs
   - Surrogate decision makers
   - Resuscitation and emergency treatment
   - Should occur early in course
   - Discussions about
     - Tube feedings
     - Initiate or continue cancer chemotherapy
     - Deactivate implantable defibrillators

Palliative Care’s Crucial Role

- Palliative care has repeatedly been demonstrated to improve quality of care. Specifically, it improves quality of life for the person and their family in terms of symptom burden, family well-being and practical supports, communication about what to expect in the future and treatment options concordant with person and family-determined goals for care.
• “In the practice of our art it often matters little what medicine is given, but matters much that we give ourselves with our pills.”
Bibliography


Quill TE, Abernethy AP. Generalist plus specialist palliative care—creating a more sustainable model. NEJM 2013; 368(13): 1173-75

The SUPPORT Principal Investigators. 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). JAMA 1995; 274(20): 1591-98


