Palliative Care I&II: a Primer for Guardians

Chris Ruskey, MD
Medical Director, Palliative Care

Learning Objectives and Session Outlines:

**Session I: Palliative Care What it is and Why it Matters for my client**

- **Learning Objectives:** Participants will...
  - Gain an understanding of medical ethics, philosophy and approach of Palliative Care that help maximize each client’s care, throughout the care continuum.
  - Appreciate the data that support palliative care’s role in helping achieve the Triple Aim +1:
    1. Client and Family Satisfaction
    2. Quality of Care
    3. Efficiency
    4. Professional & Institutional Integrity

- **Outline (8:15-9:45):**
  - Case introductions
  - Ethics, Principles and Application
  - Definition and explanation of Pall Care
  - Case I, a client with heart & lung disease; group.
    - Pall approach to chronic disease management
Learning Objectives and Session Outlines:

Session II: The Palliative Approach - Practical Integration of Palliative Care with Client Services.

- **Learning Objectives:** Participants will...
  - Know what to expect from a palliative care consultant.
  - Be capable of identifying quality palliative care service providers in your community and know how to best engage and integrate their services with client care.
  - Apply the palliative approach through skills learned in client centered, interdisciplinary, case-based exercises.

- **Outline (10:00-11:30):**
  - **Case II, a client with moderately advanced dementia:** group problem solving and discussion
    - Palliative approach to participants with dementia.
  - **Case III, a client with advanced cancer:** group
    - Palliative approach to clients with advanced cancer
  - Tools, Summary and Concluding remarks

Disclaimers/Conflict of Interest

- Dr. Ruskey is an employee of Interim Healthcare of Southern Colorado, a franchise of Interim HealthCare Inc.. Views expressed in this presentation and materials do not necessarily reflect the views or interests of Interim HealthCare or its subsidiaries.

- This presentation and materials included or referenced are not intended to be comprehensive and do not constitute medical or legal advice.
Session I:

Palliative Care What it is and Why it Matters for my Client

Case Introductions:

I. Ms. Smith, a client with heart & lung disease

II. Mr. Ortega, a client with moderately advanced dementia

III. Ms. Jones, a client with advanced cancer
Ethics

• NGA Ethical Principles

• Medical Ethics

NGA Ethical Principles:
“A guardian….“

1. ..treats the person with dignity. (Standard 3)
2. ..involves the person to the greatest extent possible in all decision making. (Standard 9)
3. ..selects the option that places the least restrictions on the person’s freedom and rights. (Standard 8)
4. ..identifies and advocates for the person’s goals, needs, and preferences. (Standard 7)
5. ..maximizes the self-reliance and independence of the person. (Standard 9)
6. ..keeps confidential the affairs of the person. (Standard 11)
7. ..avoids conflicts of interest and self-dealing. (Standard 16)
8. ..complies with all laws and court orders. (Standard 2)
9. ..manages all financial matters carefully. (Standard 18)
10. ..respects that the money and property being managed belongs to the person. (Standard 17)
Medical Ethics

• **Important general values/terms:**
  - Stakeholders
  - Patient/family centered care
    - Goals, values, preferences
  - Medical decision-making capacity
  - Competence (court determined)
  - Professionalism
  - Proportionality

• **EOL terms and considerations:**
  - No ethical distinction between refusing or discontinuing a medical intervention
  - Principle of Double Effect
  - Medical futility

• **Primary model: Principilism**
  - Autonomy
  - Beneficence
  - Non-Maleficence
  - Social Justice

• **Other models:**
  - Narrative Ethics
  - Feminist Ethics
  - Etc.

Palliative Care: Increasing Awareness

• [President's Message re Pal Care - aarp.org](http://aarp.org)
A few #s to consider:

- Palliative care teams within U.S. hospitals with 50 or more beds: ↑ 164%, from 658 in the year 2000 to more than 1,700 today. Palliative care is proving its value and is now considered a standard of care within hospitals and other care environments.

- Consumers: 92% report they would be likely to consider palliative care for themselves or their families if they had a serious illness; 92% believe patients should have access to this type of care at hospitals nationwide.

- 90 million Americans are living with serious illness, and this number is expected to more than double over the next 25 years.


Hospice: as with Pal Care:
- Advanced disease; Life expectancy ≤ 6 mo
- Proscribed benefits, per Medicare

Pal Care:
- Whole Person; mind, body and spirit
- Person-centered
- Interdisciplinary
- Coordinated
- From onset disease
- Across settings of care
Pal Care:

- The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need or desire for other therapies.

- Palliative care is both a philosophy of care and an organized, highly structured system for delivering care.

- Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

- Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s).

Pal Care:

- Evaluation and care is comprehensive, patient-centered, honoring role of the family/support as desired by the patient in decision-making and care.

- Affirms life by supporting the patient and family’s goals for the future, possibly including their hopes for cure or life-prolongation, peace and dignity throughout their journey.

- Utilizes the expertise of various disciplines in order to adequately assess and help manage the complex needs of seriously ill patients and their families: physicians, nurses, social workers, chaplains, nutritionists, rehab specialists, pharmacists and others.

- Leadership, collaboration, coordination and communication are key elements for effective integration of these disciplines and services.
Pal Care, Levels of Expertise:

**Historic Care Map:**

- Therapy with Curative Intent
- Symptom Rx; Supportive Care
- Hospice

Disease Presentation → 6 months / Death → Bereavement Care
The Palliative Care Continuum:

Three Forms of Palliative Care Provision:

- Palliative Approach or Generalist Palliative Care
- Specialist Palliative Care Services
- End of life (terminal) care
Where there is approximately one cardiologist for every 71 persons diagnosed with a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative medicine physician for every 1,200 persons living with a serious or life-threatening illness.

Ideal State: Matching Needs and Services

- Hospice Services
- Specialist Palliative Services
- Generalist Palliative Care

Complexity

i.e.: Cardiac disease
heart failure, arrhythmia, heart attack

Elevated blood pressure
**Palliative Care Potential: Triple Aim +1**

1. Client and Family Satisfaction  
2. Quality of Care  
3. Efficiency  

+1: Personal, Professional & Institutional Integrity

---

**Pal Care Benefits:**

1. Patients and Families:  
   - Symptom relief  
   - Personal/social support  
   - Improved QOL

2. Providers  
   - Support in caring for patients and families with complex needs  
   - Relief knowing patients receiving best, most appropriate care at a critical time in their lives

3. The “system”  
   - Improved quality  
   - Decreased “futile” care  
   - Cost savings
Prognostication:

Optimism in survival estimates given to cancer patients

The median survival physicians would communicate to patients was 90 days, the median formulated survival was 75 days, and the median observed survival was 24 days.

Data from Lamont, EB, Christakis, NA, Ann Intern Med 2001; 134:1096.
Prognostication & Indicators of Palliative Need

- General health status (depressed mood, agitation, decreased intake)
- Increasing clinic, ER visits or hospitalizations.
- Symptoms (dyspnea, cough, nausea/vomiting, diarrhea, pain)
- Signs (weight loss, low blood pressure, weakness, delirium, etc.)
- Recurrent or progressive skin breakdown or infections in spite of optimal care
- Laboratory (Oxygen levels, blood counts, liver function, kidney function, etc.)
- Decline in functional or cognitive performance scales (PPS, ECOG, FAST, etc.)
- Progression to dependence on assistance with additional activities of daily living
Common Wisdom….

Accurate prognostication is often difficult, so instead of asking: “Will this client die in next 1-2 years?”

Consider:

“Would I be surprised if this client were to die in the next 1-2 years?”...

If you would not be surprised, consider consulting palliative for palliative care services for assistance.

Disease Trajectories:

• Chronic, slowly and steadily progressive
  • i.e. Dementias

• Chronic with episodic exacerbations
  • i.e. Emphysema or congestive heart failure

• Rapidly progressive
  • i.e. certain cancers
Summary: Palliative Care Benefits

• Suffering occurs in many domains for both the patient and the family; Palliative care personnel are experts in symptom management, patient and family support, emotional and spiritual care.

• Palliative care involvement promotes formulation of advanced directives and detailed care planning early in care.

• As disease advances, palliative care team can help identify evolving needs and coordinate best care.

Case I: Ms. Smith
What is the role for palliative care and/or hospice services in caring for patients with chronic disease?

“We must all die. But if I can save him from days of torture, that is what I feel is my great and ever new privilege. Pain is a more terrible lord of mankind than death himself.”

Albert Schweitzer
Palliative Approach to Chronic Disease Mgmt:

- Clarify reason for consultation; Coordinate care
- Thorough review of patient’s medical record
- Meeting with patient, family, caregivers.
- Establish patient’s values, preferences and goals of care.
- Create a care plan that works to maximize comfort and quality of life, taking into consideration above, plus:
  - Empowering patient, family, caregivers: i.e. explaining health, disease and what to expect; reviewing medications and establishing plan for exacerbations/symptom management
  - Reframing hope, balancing disease realities with patient’s desires and dreams
- Close follow-up and Communication

20% of all Medicare beneficiaries have 5 or more chronic conditions, and 66% of Medicare spending goes to cover their care. This group is most likely to benefit from palliative care. Recent studies indicate that by closely matching treatments with patients’ goals, and improving their quality of life, palliative care can provide substantial cost reduction.

Session II:

The Palliative Approach - Practical Integration of Palliative Care with Client Services.

Brief Review of Session I
Case II: Mr. Ortega

Dementias: a Growing Public Health Problem

Prognostic Factors

- Partly dependent on age of dementia diagnosis: lifespan ranges from 2-20 years, median survival is 3-6 years
  - 60s to early 70s: 7-10 years
  - 90s: 3 years
- Decreased intake; anorexia
- Functional impairment
- Extrapyramidal signs
- Lower cognitive test scores

Causes of death, Patients with Dementia:

- Infection (most common - pneumonia)
  - Risk factors: eating difficulties, incontinence, immobility, behavioral disturbances
- Other comorbidities
Palliative Care Approach: Address Advanced Directives Early

- Dementia is progressive and irreversible, but in the early stages, patients can more clearly articulate preferences for care.

- Relieves further burden on caregivers by delineating specific care and treatment that is or is not desired.

Palliative & Hospice Care with Dementias, Palliative Approach:

- Cognition/Behavioral Issues: Depression, Anxiety, Frontal Release, Psychosis
- Pain
- Infections
- Nutrition/Hydration
Dementia is a Neuropsychiatric Illness

- 62% of patients with have a clinically significant neuropsychiatric symptom in a given month
  - Apathy 36%
  - Depression 32%
  - Agitation/aggression 30%
  - Other symptoms: sleep disturbance, delusions, hallucinations, anxiety, disinhibition, irritability

- Psychiatric symptoms may be the most common reason for admission to an institution

Depression:

- Under-diagnosed.
- Very difficult to diagnose with certainty in advanced dementia. Time-limited trials of fast acting stimulants like Ritalin may be useful.
- Suspect if agitation, repetitive vocalizations, apathy, insomnia, food refusal and resistive behaviors occur
- Meaningful activity (i.e. soft music, gentle touch, & pets) may be effective, even in terminal stages
- Trial medication, starting with low doses....monitor and adjust as indicated.
Anxiety:

- Source? ... Rule out reversible causes.
- Always try to modify environment/process prior to resorting to medications
- Minimize anxiety enhancing medications:
  - i.e. Steroids, stimulants (asthma meds, etc.)
- Cautious use of medications; tailored to individual, low dose, monitor and adjust as indicated

Frontal Release

- Loss of normal control of behaviors, reactions and social inhibitions
- Manifest as labile mood, sexual disinhibition, cursing, etc.
- Treatment options:
  - 1st: rule out reversible causes
  - Environment, Behavior mod., etc.
  - Medications: Antidepressants (i.e. SSRI for sexual disinhibition), Anticonvulsants (valproic acid = Depakote), NMDA blockers (Namenda), Hormonal therapy (i.e. consider estrogen for sexual disinhibition)
Psychosis:

- Delusions and hallucinations are common in advancing dementia
- They may be pleasant or terrifying; tailor approach accordingly
- Provide low-stimulus environment
- Cautious use of newer antipsychotic medications for disturbing, unremitting symptoms; trial, with periodic dose reductions

Pain assessment and management:

- As dementia advances, must rely on non-verbal cues and observations.
- Take into account the whole person, goals of care, function, comorbidities, resources, etc.
- Encourage activities, social engagement, purposefulness as much as is possible.
- Trial non-medical treatments: distraction, cold/warm packs, massage, touch therapy, etc.
- If medications required:
  - Avoid side effects, considering individuals’ particular characteristics, health issues, etc.
  - Lowest possible doses; WHO ladder
  - Topical formulations
Infection in Patients with Advanced Dementia:

- Infection is not just a complication, but is commonly an inevitable consequence.
- Antibiotics often have limited effectiveness in severe and terminal dementia.
- Repeated courses of antibiotics lead to development of resistant strains of bacteria that still result in death.
- Hospitalization has not been shown to improve outcome in pneumonia in these circumstances. Death and further impairment occur more often when patients with advanced dementia are hospitalized.

Eating difficulties:

- Includes food refusal and/or dysphagia.
- May be from poor appetite, medications, depression, etc.
- May also “forget” how to open mouth to receive food and how to swallow.
- Preferences change as disease progresses... so adapt expectations and care to patient’s natural, evolving state.
Nutrition:

- Success in promoting feeding requires time and multidisciplinary involvement
- Food refusal may respond to antidepressants
- Tube feeding is not recommended in advanced dementia
  - No improvement in function, quality of life, or comfort; no weight gain or prevention of aspiration
  - Hospitalized patients with advanced dementia and decreased oral intake: 50% chance of death at 6 months with or without tube feeding
- Patients often aren’t hungry in advanced dementia...so may be no comfort benefit.

Hydration at end-of-life:

- Thirst can typically be easily palliated with good oral care moisture swabbing.
- Dehydration is beneficial when dying inevitable
  - Less peripheral edema
  - Decreased pulmonary secretions- less shortness of breath, respiratory distress, airway edema
  - Less vomiting and diarrhea
  - Decreased pain sensation

References:

JAMA 1999 282:1365-70
Arch Int Med 2001 161:594-9
General Comfort issues

- Try to avoid medical interventions that produce discomfort or frighten:
  - feeding tubes, lab draws, restraints, IV’s, etc.
- Suspect pain, constipation, and urinary tract infection in any demented patient who is newly combative with cares, is excessively restless, has repeated vocalizations, or increased irritability

Hospice Admission guidelines for Persons with Advanced Dementia

- Inability to ambulate
- Inability to communicate intelligently
- History of frequent infections
- History of skin breakdown
- Difficulty swallowing
- Significant weight loss
Case III: Ms. Jones

The “Case” for Pal Care Participation in Care of Pts with Advanced Cancer:

- New England Journal of Medicine, 2011
- American Society of Clinical Oncologists
Original Article

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


N Engl J Med
Volume 363(8):733-742
August 19, 2010

Kaplan–Meier Estimates of Survival According to Study Group
The Provisional Clinical Opinion

Based on strong evidence from a phase III randomized clinical trial (RCT), patients with metastatic non-small cell lung cancer should be offered concurrent palliative care and standard oncologic care at initial diagnosis. While a survival benefit from early involvement of palliative care has not yet been demonstrated in other oncology settings, substantial evidence demonstrates that palliative care – when combined with standard cancer care or as the main focus of care – leads to better patient and caregiver outcomes. These include improvement in symptoms, quality of life (QOL), and patient satisfaction, with reduced caregiver burden. Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced utilization of futile intensive care.

The Provisional Clinical Opinion, cont’d

While evidence clarifying optimal delivery of palliative care to improve patient outcomes is evolving, no trials to date have demonstrated harm to patients and caregivers, or excessive costs from early involvement of palliative care. Therefore, it is the Panel’s expert consensus that combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden. Strategies to optimize concurrent palliative care and standard oncology care, with evaluation of its impact on important patient and caregiver outcomes (e.g. QOL, survival, healthcare services utilization, costs) and society, should be an area of intense research.
Palliative Approach to Advanced Cancer Mgmt:

- Clarify reason for consultation; Coordinate care
- Thorough review of patient’s medical record
- Meeting with patient, family, caregivers.
- Establish patient’s values, preferences and goals of care.
- Create a care plan that works to maximize comfort and quality of life, taking into consideration above, plus:
  - **Empowering** patient, family, caregivers: i.e. explaining health, disease and what to expect; reviewing medications and establishing plan for exacerbations/symptom management
  - **Reframing hope**, balancing disease realities with patient’s desires and dreams
- Close follow-up and Communication

Considerations and Tools for Guardians

I. Improve overall awareness of Palliative Care and Hospice options in educational materials to patients and providers

II. Consider specific “triggers” for patients and providers within flowsheets/protocols:

1. General: advanced directives
2. Disease/state specific....
   A. Palliative care protocols
   B. Palliative care consultation
   C. Hospice indicators
   D. Hospice consultation
Five Essential Elements of Therapeutic Planning:

1. Identify and work closely with surrogate decision maker(s) and other interested parties.
2. Discuss overall goals for care.
3. Establish understanding and clarity regarding Overall Comfort vs Cure emphasis.
4. Know interventions desired in various situations: CPR, tube feedings, surgery, transfusions, dialysis, antibiotics, etc....Weigh risks and benefits
5. Have clear understanding of how to best support the patient and their loved ones through this stage of life.

Difficult Conversations:

Have a seat Kermit. What I'm about to tell you might come as big shock...
• Seven Step Approach to Communication:

1. Prepare for the discussion
2. Establish what the patient (and family) knows
3. Determine how information is to be handled
4. Deliver the information
5. Respond to emotions
6. Establish goals for care and Rx priorities
7. Establish a plan


Assess the Patient/Client’s Understanding of their Prognosis

“What has your doctor told you about your condition?”

“Have they talked to you about what this latest problem might be?”

“From what you know, do you think your (cancer, heart disease, etc.) will get better, worse or stay the same over the next month…year…?”
Handling Information:

Remember, even though most patient/families want clear, direct communication regarding their conditions and care options, this is not always so. Occasionally such information is not appropriate for the patient (capacity, clinical circumstances, etc.), or a patient/family have communicated that they do not want such information directly.

BREAKING BAD NEWS

- BE AWARE OF THE STAGES OF GRIEF AND PROVIDE A HIGH LEVEL OF SUPPORT

SHOCK
DENIAL
ANGER
FEAR
BARGAINING
ACKNOWLEDGEMENT
ACCEPT THE PATIENT WHERE THEY ARE AND DEFINE THE PATIENT’S GOALS FOR CARE

WHAT QUESTIONS DO YOU HAVE?

"WHAT ARE YOUR HOPES AT THIS POINT?"

“IS THERE ANYTHING IN PARTICULAR THAT YOU ARE AFRAID OF?”

HOPE:

Hope is the expectation of something better to come in the future

It’s meaning is unique to each of us but Hope is common to all.

Hope gives strength and courage to battle illness but also wisdom to find meaning in life and death.

Modern medicine focuses hope on prolonging life, on “cures”
“Considering how you would have someone appreciate you and respect you as a unique individual, with a unique style, while in a hospital room penetrated intermittently by strangers, is an exercise that promises to teach caregivers about the import of attending to the unique characteristics of each patient, a lifetime of events that reflects a unique style of another human being lying under a bedsheet.”

Matt Stolick in “Dying to meet you...”

Summary: We have...

- Considered the complexities of life, decision-making and care encountered by a young person with progressive cancer who is experiencing multi-dimensional suffering.
- Applied Ethical Principles from NGA and the medical ethics model to our thinking about medically-hastened dying.
- Reviewed the history, use and outcomes of medically hastened death in Colorado and other states.
- Shared personal, professional and organizational approaches to legislation, policies and preparation of our response to requests for assistance at end-of-life.
Resources:

- American Academy of Hospice and Palliative Medicine
- American Association of Retired Persons
- American College of Legal Medicine: http://www.aclm.org/
- American Medical Directors Association
- American Society of Clinical Oncology
- American Society of Law, Medicine and Ethics: http://www.aslme.org/
- Colorado Hospital Association: https://cha.com/
- Colorado Dept of Health and Environment: https://www.colorado.gov/cdphe
- National Hospice and Palliative Care Organization

Articles:

- Palliative Care: A Key to Living With Dignity: This growing approach to care is not limited to end-of-life cases, by Jeannine English, AARP President in AARP The Magazine, December 2015
- Quantity and Quality of Life: Duties of Care in Life Limiting Illness, Atul Gawande, JAMA, Jan 2016, p 267-269.