Palliative Care 101: practical tips for your practice

Session 1 Objectives:
- Palliative Care and Hospice
  - Background
- Difficult conversations
  - Approach, tips and strategies for care goal discussions
- POLST Registry and updates
  - What you need to know

Session 2 Objectives:
- The Medicare Hospice Benefit
  - Presentation
  - Panel Case Review

What is Palliative Care?
- Care at any stage of an advanced illness along with all other appropriate medical treatment
- Expert management of pain and other uncomfortable symptoms
- Eases transitions between care settings (such as hospital, nursing facility, home)
- Goal is quality of life
- Focuses on the whole person: body, mind, and spirit

What is Palliative Care?

HELPS educate patients and families about prognosis, health care options, establish realistic care goals
- Identifies community resources to meet patient goals
- Facilitates communication between patient, family members, and health care providers
- Team approach to care involving all disciplines (physicians, nurses, social workers, spiritual care providers, therapists, pharmacists)

CMS Definition:
“Palliative care means patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.”

24 FR 32204, June 5, 2009
Medicare Program: Conditions of Participation - Final Rule
Palliative Care

Common illnesses:
- Cancer
- Heart disease (heart failure, coronary disease)
- Lung disease (emphysema, pulmonary fibrosis)
- Dementia
- Parkinson’s Disease
- Stroke
- Amyotrophic Lateral Sclerosis (Lou Gehrig’s Disease)
- AIDS

Foundations of Palliative Care

- Dying is normal.
- Advance care planning is important.
- Patients and families need help with coordination of care and services.
- Medical care should be delivered based on the patient’s goals and values.

Relationship of Palliative Care to Hospice

- Hospice is both a philosophy and a health care reimbursement system
  - Restrictions on eligibility (< 6 months prognosis)
  - Restrictions on treatments (focus on comfort)
- Hospice is a subset of palliative care, for patients who meet the hospice eligibility requirements.

Conceptual Shift for Palliative Care

Primary Palliative Care
- Care goal discussions
- Symptom management
  - Disease-specific modifying medications
  - Comfort medications
- Referrals to community resources

Subspecialty Palliative Care
- Complex care goal discussions
  - Conflict
  - Unrealistic care goals
  - Lack of clear decision maker
- Complex symptom management
- Complex care planning and referrals
  - Assistance with prognostication, hospice eligibility
Domains of Suffering - “Total Pain” Concept

- Physical
  - pain, nausea, dyspnea, agitation, constipation, anorexia, skin wounds...
- Emotional or Psychological
  - anger, anxiety, depression
- Social/Interpersonal
  - family issues, financial stressors
- Spiritual/Existential
  - faith, meaning, closure, legacy

Advanced Illness Management Program

- Realistic patient and family-centered care goals
  - Reevaluated throughout the duration of illness
  - Empowering patients and families about their healthcare choices
- Expert symptom and comfort management
  - Whether pursuing aggressive life prolonging care or comfort measures only
  - Independent of prognosis

Advanced Illness Management Center of Care

- Develop seamless care flows for patients with advanced illnesses throughout our regional health care system
- Collaboration
  - Regional physicians, practices and community programs
  - AIM Program
  - Hospice Programs
  - COIPA

Advanced Illness Management Program

- Intended for pts with life limiting illness with prognosis < 2 years
- Cohesive interdisciplinary approach to palliative care for patients with advanced illness
- AIM Subspeciality Consultations
  - St. Charles Bend since 2009
  - St. Charles Cancer Center since 2010
  - Outpatient AIM Consultation coming spring 2012

Advanced Illness Management Program

- Tools and support for providers in Central Oregon managing patients with advanced illnesses
- Potential triggers for palliative care/care goal discussion (by PCP, disease-specific subspecialist, or AIM Team Provider)
  - Uncontrolled symptoms
  - Unclear care goals
  - Care goal discussion for pts with COPD or CHF with 3 or more hospitalizations within 6 months

Difficult Conversations

Why are care goals discussions so difficult for us?
- Uncertainty of reactions
- Feeling inept with handling reactions
- Professional sadness or feelings of failure
- Anxiety to witness strong emotions from patient and family
- Responding that curative modalities have failed
- Acknowledging mortality
- Difficulty honoring patient’s desire to stop aggressive/invasive treatments

Barbara Glidewell, Oregon Statewide Palliative Care Conference, June 2011. "When you dread going in the room..."
Difficult Conversations

Why are care goal discussions so difficult for the patient and family?

Fear of:
- physical symptoms, dying process
- abandonment by their healthcare team
- loss of functional status
- having adequate caregiving
- being a burden
- financial stressors

Approach:
- Recognize the patient and family are under undue stress, are afraid, are likely to use their most basic coping strategies
  - May include denial, anger, mistrust, defensiveness
  - Five stages of grief (Kubler-Ross): denial, anger, bargaining, depression, acceptance

Approach the conversation without a personal agenda for the outcome

Difficult Conversations

Care goal discussions become necessary when there is disagreement about care plan or lack of a cohesive care plan
- Patient
- Family
- Healthcare team

Often come to a head with crises

Unrealistic care goals

Prepare yourself:
- Anticipate your own reactions/emotions
- Think about possible options, what is truly medically and ethically appropriate among those
- Anticipate strategy to handle difficult interactions that may occur
- You are in control - you may stop any time

Set the scene
- Atmosphere
  - Provide quiet space
  - Tones
  - Attention, uninterrupted time
- Attention/listening
  - Turn off cell phones and pagers
  - Sit down
  - Listen more than you talk
  - Valuing what is said
  - Speak at last patient
- Audience
  - Who is attending in the room?
  - Who called the meeting?
  - Who is the decision maker?
Difficult Conversations

**UFO UFO**

- **Understand**
- **Fill in details**
- **Outcomes**

**Difficult Conversations**

**UFO UFO**

**Understand**

- Understand the medical situation
- Ask patient and family what they have been told, what they understand to be the medical issues they are facing
- Ask them what information they want to know to help them better understand their medical situation
- Ask them if there are things they do NOT want to discuss

**Difficult Conversations**

**UFO UFO**

**Fill in details**

- Spend time clarifying the medical situation
- Correct misunderstandings
- Answer questions about what they want to know and have not been told
- **DO NOT OFFER PROGNOSTIC INFORMATION WITHOUT GETTING PERMISSION FIRST**

**Difficult Conversations**

**UFO UFO**

**Outcomes**

- What are you hoping for?
- What do you expect to happen?
- Are there situations that you do not want to be stuck in?
- Are there medical procedures or treatments you know you do not want?

**Difficult Conversations**

**UFO UFO**

**“Help me understand your values and decision making.”**

- What makes your life worth living?
- What is important to your quality of life?
- What is important to your family/loved ones?
- What framework do you use to make medical decisions?
  - Family
  - Spirituality
  - Individual autonomy

**Difficult Conversations**

**UFO UFO**

**Feasible Outcomes**

- “Hope for the best, plan for the worst.”
- Best case scenario
- Worst case scenario
- What is unlikely to happen
- What to expect as this illness progresses
- Discuss prognosis to help planning (if patient and family are ready)
Difficult Conversations

Prognosis
- Tread carefully
- Speak broadly
  - Hours to days, days to weeks, weeks to months, months to years
- "Crystal ball", lack of accuracy
- Physicians are notoriously poor at prognostication
- Longer relationship with pt makes prognosis less accurate
- Error more likely to overestimate prognosis

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Fromme EK et al. JPM. 2010 Dec;13(12):1439--44. Epub 2010 Dec 3.

Difficult Conversations

Identify emotions
- Acknowledge that emotion being expressed
- Explore what is behind the emotion
  "It seems like you are really frustrated about your weakness."
  "You seem really angry about your situation."
  "I can see this is really upsetting to you."
  "What is the scariest part for you?"

Validate feelings
- Legitimize the appropriateness/normalcy of reaction
  "It is understandable you are sad."
  "Anyone receiving this news would feel devastated."

Express empathy
- Being emotionally able to imagine what patient/family are going through
  "I wish things were different for you."
  "You can provide support just by being quiet and listening."

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Summarize consensus, disagreements, decisions, and plan
Caution about unexpected outcomes
Identify family spokesperson for ongoing communication
Offer follow up
Enlist additional support
  - Social work, spiritual care, community resources

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Debrief Difficult Conversations

- With a HIPAA protected colleague or team
- How you responded
- How you might do it differently next time
- Purpose of debrief to relieve the internalized stress of an upsetting event or situation
  - Avoid emotional baggage

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Difficult Conversations

Summary
- Difficult conversations are difficult!
- They take time and energy, easier with some basic skills and tips
- Approach to ensure effective discussion
- Self care
**Oregon POLST Registry**

- Signed into law July, 2009
- Law became effective December 1, 2009
- Does NOT require every patient to have a POLST
  - Intended for pts with advanced illness or frailty
- DOES require health care professional to submit POLST to Registry when completed (unless patient chooses to opt out)

**POLST Registry**

- POLST often not found immediately by EMS first responders
- First responders can call Registry Hotline 24/7 when paper form cannot be found immediately
- Secure and accurate database housed at OHSU Emergency Communications Center
- As of May 2011
  - Over 54,000 POLSTs in registry (7900 13% not ready due to missing date or signature or illegible)
  - Over 600 calls to Registry Hotline

**Newest POLST Version – June 2011**

- Demographic Section:
  - Instructions revised, formatting changes
- Section A: Cardiopulmonary Resuscitation
- Section B: Medical Interventions
  - Medical interventions and treatment plan (language revised, antibiotics section deleted and added here)
- Section C: Artificially Administered Nutrition
- Section D: Documentation of Discussion
  - Patient or surrogate signature (moved from back)
- Section E: Provider name and signature and date (requirements MD, NP or PA clarified)

**Old ——— New POLST**

- Use new forms now
- Old forms remain valid but should be updated on new form with demographic information
- Minimum completion requirement is Demographics, Section A Code Status, and Section E Provider Signature

**How to abide by Registry Law**

- Develop procedure for office/facility staff to submit newly completed POLST forms to Registry
  - Copy both sides of form
  - Give original to patient
  - Fax copy or mail copy (fax and address on back of new POLST form)
  - Registry will provide confirmation of receipt to sender and refrigerator magnet to patient with POLST ID number and confirmation for easy reference and display
Palliative Care 101

- Palliative Care & Hospice
- Difficult Conversations
- POLST Registry

Next week:
- Palliative Care 101 – Part 2
- The Hospice Benefit