Palliative Care in Long Term Care Settings

Dr. Aisha Choudhry,
Dr. Dana Delach, and
Deb Groath, DNP
Palliative Care and Hospice

MMC-NI: Who We Are

• Founded in 1916
• Major referral center for northern Iowa and southern Minnesota
• Employs over 2400 individuals
• Serves 14 counties
• Includes contract affiliations with eight (8) rural hospitals and 46 physician clinics in surrounding counties
• 346 licensed beds; 206 staffed beds

MMC-NI: Who We Are

• Family Practice Residency Program – 18 residents
• Cardiology Fellowship – 6 fellows
• Interventional Cardiology Fellowship – 1 fellow
• Hospice and Palliative Medicine Fellowship – 1 fellow
  – Community based program
  – Hospice inpatient unit – 6 bed
  – Robust palliative care outpatient program
Our Palliative Care Team

• Program start-up December 2006
• 24/7 inpatient, outpatient consultative service
• Board certified physician led model, 2 physicians, 1 nurse practitioner, 1 fellow, 1 nurse, 1 social worker, 1 secretary, prn spiritual care
• Providers cover hospice services as well - inpatient and outpatient
Our Team Celebrations

- Continued annual growth in inpatient consults
- Achieved 6% penetration rate (palliative consults/total hospital admissions)
- Continued annual growth in ICU consults
- PERT continues to avoid hospitalizations
- Graduation of 5 fellows (4 board certified, 1 board eligible)
- Continued growth in nursing home visits

Differentiating Hospice and Palliative Care

- Hospice is reimbursed under the Medicare Hospice Benefit and requires:
  - No life-prolonging therapies
  - Certification by two physicians as having a life expectancy of six months or less (especially important restriction for nursing home residents due to unpredictable courses of heart disease, stroke, and/or dementia)

- Palliative care:
  - Can be delivered at the same time as life-prolonging disease treatment.
  - Eligibility depends on need, not prognosis.
  - Reimbursed by Medicare, Medicaid, and most third party payers.
PALLIATIVE CARE IN THE LONG TERM CARE SETTINGS

Palliative Care in Nursing Homes

“The integration of palliative care into nursing homes offers a compelling solution. Palliative care is specialized medical care for people with serious or complex illness, focused on providing patients with relief from symptoms and distress,” says Dr. Meier.

- CAPC News Bites January 15, 2015

Making the Case for Palliative Care in Nursing Homes

• Advances in medicine and the aging baby boomer generation contribute to the growing population of those living longer and with chronic illness.
• The number of people living in long-term care nursing facilities in the US is expected to double to more than 3 million by 2030.
• Nursing homes are responsible for both the long-term management of these patients and their care at end of life.
The Benefits of Palliative Care

• Improved quality of care
• Increased patient and family satisfaction
• Prolong survival
• Reduced mortality via:
  • Reduced iatrogenesis
  • Crisis prevention through more effective symptom management
  • Reduced depression
• Decreased emergency room visits and hospitalizations

Barriers to Palliative Care in Nursing Homes

• Regulatory
  – Quality measures with emphasis on rehabilitation rather than comfort
  – Skilled Medicare Benefit following hospitalization vs Medicare Hospice Benefit
• Shortage of palliative care trained staff

Models of Palliative Care Delivery in Long Term Care

• Long term care driven palliative care consults
• Long term care employs own palliative care team
• Partnering between hospice/palliative care and long term care within the community
WHAT PALLIATIVE CARE CAN DO FOR YOU

Populations Served

- Seriously/chronically ill patients
  - Lung disease
  - Heart disease
  - Neurological disease (ALS, Parkinson’s, Dementia)
  - Cancer
- Overall decline functionally
- Unmanaged pain

Contents of a Palliative Care Consult

- Code status
- Plan of care/goals of care
- Difficult decision making (feeding tubes, treatment interventions)
- Treatment options
- Re-hospitalizations or ED visits
- Pain management
- Non pain symptom management
- Prognosis discussions and indication
For many, the end-of-life journey begins one to three months prior to death.
Domains of Suffering at End-of-Life

- Physical – pain, breathlessness, restlessness
- Psychological – depression, anxiety, agitation
- Social – financial, family/friends, withdrawal
- Spiritual/existential – “Why me?”, seeking closure, nearing death awareness
- Cultural – identify cultural differences and needs accordingly

Case Study #1

- 82 year old female in a long term care facility for the past 3 years. Resides there with her husband. She was recently moved to another area due to behavior.
- She had 3 hospitalizations over a 15 day period due to behavior changes, ongoing UTI.
- History includes Alzheimer Dementia, frequent UTI’s, osteoarthritis, hypothyroidism, hip replacement, and depression.

Case Study #1 continued

- Palliative care team first met her during her second hospitalization. We were asked to address probable pain as a source of her agitation.
- Third admission consulted for goals of care.
- Son revealed an overall decline over a 2 month period including decreased eating, less communication with husband and family, and sleeping much of the time.
The Dying Experience

One to three months prior to death:

- Withdrawal from the world around them and going within
  - No more interest in newspapers or television
  - No more interest in visits from friends
  - No more interest in extended family visits
  - Sleeping more
  - Less communication with others – touch has more meaning, words less

The Dying Experience

One to three months prior to death continued:

- Food
  - Takes on less meaning
  - No longer needed to energize the body
  - Decreased intake of foods hard to digest (meats, etc)
  - Liquids preferred to solids
  - Energy needed moves from physical to spiritual
  - IT IS OK NOT TO EAT (but difficult for those around to understand)

Symptom and Treatment Needs

(1-3 months prior to death)

- More sleep and less food = increased weakness and increased fall potential
- More time in bed = increased skin care and possible joint pain, etc.
- Pain medication = increased fall rate
- Family and staff education
  - Don’t force food
  - More attention to fall prevention
  - More attention to skin care
  - Withdrawing should not be taken personally
Review Case #1

• Son reported withdrawing from food, interaction, activity, and 2 falls in the past month.
• Behavior changes –
  – Could reflect pain from less activity or UTI
  – Could reflect advancing dementia
• Added fentanyl 12 mcg per hour patch which did help her agitation but would increase her fall risk.
• Admitted to hospice at the care center with less than 6 month prognosis – showing signs of months to death.

Nearing Death Awareness

Phenomenon

• Often misinterpreted as confusion
• Special to and experienced only by the patient
• Different from terminal restlessness or terminal agitation

Nearing Death Awareness

"Nearing Death Awareness often includes visions of loved ones or spiritual beings, although they don’t necessarily signal death's imminence."

- Final Gifts
Nearing Death Awareness

"Dying people often seem to know when their death will occur, sometimes right down to the day or hour. Surprisingly, they often face this knowledge not with fear or panic, but rather with quiet resignation."

- Final Gifts

Case Study #2

- 85 year old male hospitalized monthly for the past 3 months. He has colon cancer diagnosed 6 months ago and not tolerating treatment well.
- Most recent hospitalization for weakness and found to be septic. Aggressive treatment started.
- Other history includes hypertension and atrial fibrillation on anticoagulation therapy.

Case Study #2 continued

- Recently admitted to long term care, where his wife resides as well (with dementia).
- Palliative care team consulted to discuss goals of care and symptom management.
- Family had discussed an overall decline since surgery 3 months ago – increased weakness, decreased appetite, inability to live alone, increased pain.
The Dying Experience

One to two weeks prior to death:
- Sleeping most of the time
- Seeing and talking to people who have died
- Terminal restlessness
  - Inability to relax
  - Picking at clothing, bed sheets, air
  - Confusion/agitation
  - Trying to climb out of bed

One to two weeks prior to death continued:
- Physical changes
  - Lowered blood pressure
  - Increasing or decreasing pulse rate
  - Increased perspiration
  - Skin color changes – pallor, cyanosis, etc.
  - Breathing changes – apnea, puffing/blowing lips when exhaling, congestion, non-productive cough

Symptom and Treatment Needs (1-2 weeks prior to death)
- May need comfort medications for pain, restlessness, and dyspnea
- Family and staff education
  - Food and fluid not needed as much if at all
  - Less fall risk due to mainly in bed
  - More attention to skin care
  - Physical symptoms will fluctuate
  - Nearing death awareness
  - Spiritual and emotional support
Review Case Study #2

- Conversation with palliative care (when alone) about his son (nearing death awareness).
- Continued cognitive and physical decline with tachycardia, tachypnea, unresponsiveness.
- Family continued to have difficulty with seeing decline and letting go.
- Patient died day 4 of hospitalization with comfort care in place.

The Dying Experience

**Days to hours prior to death:**
- Possible surge of energy
- Increased restlessness
- Irregular breathing
- Pulse may become more rapid and weak
- Mottling (purplish blotchy knees, hands, feet)
- Decreased urine output
- Less responsive, glassy eyes may be partially open
- Fish out of water breathing

Symptom and Treatment Needs (Days to hours prior to death)

- Manage restlessness, dyspnea, pain, etc.
- Most frequently used medications in the care centers at end-of-life:
  - Haldol for agitation – may be crushed
  - Liquid morphine for pain and respiratory distress – may use SL
  - Lorazepam for anxiety – may be crushed
  - Atropine drops for excess secretions – use SL
- Family and staff education
  - Surge of energy and renewed hope
  - Hearing last to go
  - Be with, use touch, tell stories
Terminal Restlessness

• Terminal restlessness and terminal agitation interchangeable.
• Very common symptom at end-of-life and include the following:
  – Inability to relax
  – Wanting to do things but not knowing what
  – Picking at the clothing, sheets, air
  – Increased confusion
  – Trying to climb out of bed
• Often seen 1-2 weeks prior to death but may intensify in last few days or hours.
• Has a negative impact on the dying process for patient, family, and staff.

Terminal Restlessness

• Antipsychotics (haloperidol) used most frequently to treat.
• Benzodiazepines (lorazepam) may be used as well but may cause increased agitation in some.
• In the long term care setting, use of antipsychotics and benzodiazepines are scrutinized and are associated with increased falls.
• Atypical antipsychotics (Seroquel, Risperdal) are better accepted but not as useful at end-of-life.

Falls

• 50% of patients in long term care facilities fall each year.
• 60% of those with a history of falls in the previous year will have a subsequent fall.
• 10% of those who fall in long term care facilities result in major injuries.
• Cognitive impairment, psychotropic drug use, and benzodiazepines are all associated with higher risk of falls.
Case Study #3

- 61 year old male with a new diagnosis of a large brain tumor, suspected glioma and aggressive in nature.
- History of diabetes, hypertension, coronary artery disease.
- Tumor burden symptoms include impulsive behavior, seizures, poor short term memory, headaches, and unstable gait.

Case Study #3

- Palliative care consulted for goals of care.
- No surgical intervention, no treatment options available other than comfort care.
- Patient/family enrolled in hospice.
- Transfer to hospice inpatient for symptom management and then care center as unable to care for self at home.

Case Study #3

- Requires the following:
  - Pain medications for headaches (increased fall risk).
  - Anti-epileptics and benzodiazepines for seizure control (increased fall risk).
  - Dexamethasone for cerebral edema (increases blood sugar that already out of control thus increased fall risk).
- Impulsive behavior (increased fall risk).
Review Case #3

• Consultation with palliative care with few options other than comfort care approach.
• Continued cognitive and physical decline with falls as well.
• Family faced with difficult, rapid decision making and rapid decline (prognosis less than 3 months).
• Patient transferred to hospice inpatient for symptom management with goal of long term care placement.

Summary

• Patients at end of life:
  – Have symptoms that need to be managed to relieve patient and family suffering.
  – Often start experiencing functional decline 1-3 months prior to end-of-life.
  – Have an increase in their fall risk (multifactorial in nature) until unresponsive and bedridden.
  – Raise red flags in long term care facilities due to medications required for comfort (Haldol, lorazepam).
  – May have even experienced a fall leading to end-of-life.

Case Study #4

• 106 year old female admitted to the hospital after a fall in her bathroom at the care center. She hit her head on the sink and had severe pain.
• Was found to have a subdural hematoma, T11 Chance fracture that was unstable and movement would cause paralysis, and a left hip fracture.
• History significant for hypertension and some recent depression with lack of appetite only.
• Cognitively intact reading 4 newspapers per day.
Case Study #4

• Palliative care consultation resulted in transfer to hospice inpatient for end-of-life focusing on pain control.
• She died 6 days after her fall, as a result of sustained injuries.

Each person lives their life uniquely and each person experiences death uniquely.