Vulnerability in Older Adults:
Hospice, Palliative Care,
Pain Management,
Delirium and Care for the Caregiver

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So...we have a lot on our plate; let’s start with a big, big concept, one that is a little difficult for us all to get our hands and minds around but as they say it is “the elephant in the room”.
What is the **most common** medical event facing patients and caregivers?
death
So death and the process of dying is something important and we should deal with it effectively. 

What does that mean?

What values become important in dealing with death effectively? – for the patient, for the family?

The suffering associated with death is due to unrelieved symptoms and is a major reason for fear of death.

As caregivers we should be expert at dealing with a common, often devastating medical issue. Especially when there is much to do that makes a difference.
Teaching Aims—following this presentation participants will...

• Render effective evaluation of pain in complex older patients with assurance of optimal pain control
• Understand CMS regulations for hospice care
• Differentiate between hospice and palliative care
• Provide symptomatic management for common symptoms in chronically ill and dying patients
• Attend to the complex and changing needs of the family caregiver of demented, chronically ill or dying patient
WHAT IS PALLIATIVE CARE?

• Medical specialty focused on preventing and relieving distressing symptoms
• Improving quality of life for people facing serious illness
• It is not dependent upon prognosis
• Palliative care can be delivered along with curative treatment
• Important distinctions with Hospice care
Palliative Care Scenarios

• Any chronic illness
  – Examples – CHF, cancer, dementia, chronic renal failure, cardio-myopathy, HIV/AIDS, etc
  – Care is interdisciplinary – multiple caregivers

• Goal/principles
  – Symptom management
  – Care subject to patient’s and family wishes/needs
  – Consistent/sustained communication
  – Spiritual support (not necessarily religious)
  – Practical support for family caregivers
  – Coordination of care
Conceptual Shift for Palliative Care

Old

Life Prolonging Care

Medicare Hospice Benefit

New

Life Prolonging Care

Palliative Care

Hospice Care

Bereavement

Dx

Death

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Palliative Care & Hospice

• Palliative Care is not hospice
• Palliative Care has overlap with hospice
• Hospice – specialized care for those in the last 6 months of life
• Palliative Care is care provided independent of prognosis
HOSPICE

• Predominately a specialized form of home care
• Many health care insurers offer coverage for hospice service
• Medicare Hospice Benefit developed for Medicare beneficiaries to provide support to allow a family to care for their dying relative at home
• Hospice agency will not refuse based upon ability to pay
Hospice

• Medicare Hospice Benefit – Eligibility Criteria
  1. Physician certified prognosis of less than 6 months assuming “the terminal illness runs its usual course”
  2. Treatment goals are palliative rather curative
  3. A physician is willing to be the physician of record
  4. Hospice agencies may not use DNR status as criteria for eligibility (CMS)
HOSPICE

• Other criteria

• **Individual hospice agencies** may have their own individual additional criteria:

• For example:

• No current or planned use of blood products, artificial hydration, TPN or non-oral feeding

• A primary caregiver is in the home setting most if not all of the time
HOSPICE

• Required services that must be available to all patients under the Medicare Hospice Benefit:
  • Skilled nursing visits as needed
  • Physician medical director
  • Home health aid service for a limited time each week (not full time) for bathing, dressing, feeding
  • Psychological counseling – patient, family, community
HOSPICE

- Preparation for death – advance directives, wills, funeral planning
- Spiritual support/chaplaincy
- Volunteers
- Bereavement Program
- Inpatient care for acute symptom management or impending death
- Respite care - up to 5 days
- Provides 24/7 access to on-call RN
- Does not provide 24 hour custodial care
HOSPICE

- Medicare Hospice Benefit (MHB) Finances:
- Medicare beneficiaries may elect to activate the benefit
- To activate MHB – Medicare Part A (hospital benefit) is signed off of with respect to charges related to terminal illness
- Patient can still receive Part A coverage for hospital care for illness/disorders not related to terminal illness
HOSPICE

• MHB has benefit periods (approved time frames)
• First certification is 90 days followed by successive 60 day periods – must be recertified by the hospice medical director and primary physician
• Patients may elect to go off MHB at any time
• There is no maximum duration of time for reimbursement under the MHB
HOSPICE

• Hospice services outside of the home....
• Acute inpatient care....
• MHB patients may be admitted to hospital under the benefit for:
  • Acute symptom management, care coordinated by hospice agency and primary MD
  • Respite care – provided in acute care facility or nursing home – 5 days to give caregivers a break
HOSPICE

• Hospice services outside of the home....
• Long term care facility – can be considered “home” and hospice services provided by a Medicare certified agency
• Hospice in a long term care facility requires 2 sources of funding:
  1. Payment for hospice
  2. Payment for LTC room and board
Inpatient Hospice

• How it works
  1. Dying patient in need of hospitalization for symptom control
  2. Assess need for palliative consult to assist in symptom management
  3. Care coordination for hospice referral
  4. Patient and family choose hospice
  5. Hospice assesses and provides information
  6. Patient & Family sign on
  7. Patient then needs: Electronic discharge and readmission under the acute pain/hospice designation
Inpatient Hospice

• For the billing/payment to flow correctly a discharge and readmission need to happen with the change in service designation.

• The primary treating service does not change.

• The primary service needs to discharge and readmit inclusive of discharge summary and admit note and orders.

• The responsibilities of the bedside nurses & treating practitioners do not change.
Inpatient Hospice

• Hospice is responsible for input in symptom assessment, family support and transition in care – truly patient/family centered care
This is a good time to stop for a few questions about palliative and hospice care because we are going to move on to symptom management, specifically pain.
Pain Management
Pain prevalence and severity

• 20% of hospitalized patients suffer pain
• 50% of hospice patients experience pain
  – Moderate or severe in 85%
• Significant pain in multiple chronic diseases
  – Cancer
  – HIV/AIDS
  – Dementia
  – Congestive Heart Failure
• Undertreatment of pain is significant
  – multifactorial
What is the purpose of treating pain?
Purpose of treating pain?

Treat the pain

Treat the pain

Treat the pain
Goals of pain management?

• Treat the pain!
• Make patient’s function improved maximally
• Increase quality of life
• Decrease disability
Clinical “steps” in pain management

• Evaluate the source(s) of pain
• Evaluate conditions contributing to pain, perception of pain
• History of previous pain management
• Concomitant/co-morbid conditions
• Discuss options:
  – Goals of treatment
  – Patient’s expectations, understanding, perception
• Determine plan of management
• Discuss risks and benefits, what can be expected
• Assure mutual understanding of plan/goals/limitations
• Establishment of contract and consent i.e. agree on plan
Types of pain

• Nocioceptive pain
  – Tissue damage, inflammation, blocked viscous, infarction
• Neuropathic pain
  – Neuropathy, radiculopathy
• “Psychic” pain
  – Depression, grief, fear, anxiety
• “Memory” pain
  – Post-herpetic neuralgia, phantom-limb pain
Barriers to effective pain management

• Physician barriers
  – Inadequate assessment of the intensity of pain
  – Lack of awareness of pain modalities
  – Fear of abuse
  – Concerns for drug diversion
  – Concerns for drug side effects
    • Respiratory depression
    • Constipation
    • Nausea
    • Cognitive issues
  – Discuss “primary intention”

• Patient barriers
  – Stoicism
  – Lack of autonomy/advocates
  – Concern for addiction
  – Drug side effects
  – Family opinions
  – Cost
  – Cognitive side effects
  – Previous drug dependency or addiction
Modalities of pain management

• Medication
  – Analgesics
    • Acetaminophen (get the dose right – 1 gm tid max
      – use the max unless contraindication)
    • NSAID’s (can be problematic in elders – GI toxicity, renal failure)
    • Narcotics - opiates/fentanyl – (note multiple
delivery routes (po, im, sc, iv, rectal, pumps)
  – Adjunctive agents
    • Combination therapies
    • Anxiolytics
  – Corticosteroids
Modalities of pain management

• Medication (Continued)
  – Neuropathic medications
    • Tricyclics/SSRIs
    • Anticonvulsants
      – Carbamazepine, phenytoin, gabapentin
  – Anesthetic agents
    • Lidocaine, etc
  – Counterirritants
    • Capsaisin
      • Topical rubs, menthol
  – Placebo/homeopathic
  – Acupuncture
Pain Syndromes

• **Acute pain**
  – History is recent
    • What, where, relief factors, exacerbating factors, onset, offset
    • Disabilities
  – Physical findings often present, most prominent
  – Vital signs often affected, pt is often distressed
  – Treatment directed at relief of pain
  – Treatment is short term
  – **Management usually straight-forward**

• **Chronic pain**
  – History is remote, often very remote
    • What, where, relief and exacerbating factors, onset, offset
    • Disabilities
  – Physical findings often absent, not always
  – Vital signs not affected, pt may appear unconcerned
  – Treatment directed at pain management, disability improvement, psychologic response
  – Treatment is often chronic
  – **Management usually complex**
Clinical approach to pain management

- Acute pain is usually straight-forward
  - Treat pain effectively and completely for short duration
  - Choice of drug depends on level of pain
- **Cancer pain must be treated to max fct/QOL**
  - Treat effectively with “ladder” approach
  - No therapeutic ceiling to narcotics
- **Chronic pain is often difficult and problematic**
  - Take a careful history, do appropriate testing when indicated, get all old records
  - Make decisions based on trust in patient’s integrity unless there is objective reason to decide otherwise (ie give the benefit of doubt)
  - Treat pain effectively as necessary
  - Use a narcotic contract and discharge pt appropriately if breeched
Drug Side Effects

• Narcotics
  – Constipation
  – Nausea/vomiting – usually self-limited
  – Somnolence/delerium
  – Dependence/withdrawal

• Acetaminophen
  – Toxicity – 3-4gm maximum

• NSAIDs – gastric irritation/GI bleed/renal

• Tramadol – ceiling effect, seizures
Frequently encountered symptoms and problems in terminal patients

- Dyspnea
- Fatigue
- Xerostomia (dry mouth)
- Dysphagia/aspiration
- Anorexia/weight loss
- Nausea/vomiting
- Constipation/bowel obstruction
- Edema
We need to talk....

• About **delirium**
  – Major issue in our patients who are facing chronic illness, iatrogenic exposures and end of life care
  • Predisposing factors
    – Advanced age
    – Frailty
    – Dementia
    – Psychiatric illness
    – Malnutrition
    – Cholinergic drug therapy
    – Sensory impairment

• Precipitating factors
  – Any acute illness
  – Especially severe illness
  – Medication withdrawal
    • Including alcohol
  – Medications, especially anti-cholinergics
  – Trauma, surgery
  – Anesthetics
  – Environmental changes
Delirium – frequent causes in terminally ill patients

- Infection/sepsis
- Metabolic – hyponatremia, renal failure, dehydration, hypercalcemia
- Drugs
  - Opioids, psychotropics (benzos, antipsychotics, tricyclics), anticholinergics, drugs of abuse
- Brain metastasis
- Paraneoplastic syndromes

**Note: dementia lowers the threshold for delerium**
Delirium

• Under-recognition is common
• Adversely affects outcome
• Caregivers of chronically ill patients, especially w/ multiple meds must be good at diagnosing
• Recognition begins with a high degree of suspicion
• LOOK FOR DELIRIUM!!

• Recognition of delirium
  – Delirium vs dementia, that is the question
  – Does the patient appear vague or confused?
  – Has the patient been labeled “poor historian”, “gomer”, “social admission”
  – No focal sx of stroke, but change in condition, confusion
  – Fluctuating changes in MS?
  – May be agitated or hypoactive
Delirium – the Confusion Assessment Method, i.e. CAM

• **Criteria for delirium**

• **LOOK for**
  – Acute onset
  – Fluctuating course
    • e.g., worse in the morning, better after lunch, vice versa
  – Inattention
    • Picking at stuff (agitated), or doing little (hypoactive)
  – Disorganized thinking
    • You can’t take a history, “there and gone again”
  – Altered level of consciousness
    • Especially when variable
Delirium is not a diagnosis; it is a symptom, i.e., something is causing it

- Infection
- Metabolic disturbances
  - Renal function, lytes, etc
  - dehydration
- Myocardial infarction
- Stroke
- Medication
  - Esp anti-cholinergics
  - Esp narcotics
  - Drug (benzo) withdrawal
  - Alcohol withdrawal
- Untreated pain

- Management focused on evaluation of the underlying cause
- Drug therapy to control is problematic
  - Probably haloperidol, risperidal in low dose for older persons is best
  - Obviously withdrawal of potentially offending agents
- Caregiver attention for calm approach is vital
- Gentle reorientation helps
Care and Advice for Caregivers of Patients Experiencing Cognitive Decline

Not One, But Two Patients
Dementia - Issues for Discussion

• The nature and natural history of dementia
• Role of the physician
• Caregiver support services
• Medication and medical interventions
• Abuse counseling
• Behavioral disorders
• Intensified care
• Terminal care issues
The Nature and Natural History of Dementia

- Etiologies, cause and genetics
- Functional evaluation
- Progression “curve” and prognostication
- Stages of progression, the “eventualities”
- End of life decisions, advance directives
Roles of the Primary Care Physician and Geriatric Resource Nurse

• Support, caregiver empowerment
• Education and guidance
• Intervention decisions and referrals
• Maximizing QOL – patient/caregiver
Additional Caregiver Support

- Alzheimer Support Groups
- Coping skills
- Caregiver psychiatric treatment
- Educational information
  - “Online”, organizations (e.g., alz.org)
- Friends, neighbors and family
Medication & intervention advice

- Medication in general
- Alzheimer specific pharmacology
- Pharmacologic behavioral symptom mgmt
- Appropriate “aggressive” interventions
- Inappropriate interventions
- QOL the ultimate goal
Behavioral symptom management

- Agitation
- Confusion
- Depression
- Psychosis
- Night/day reversal
- Adverse drug side effects
Abuse counseling

- Caregiver patient abuse
- Caregiver abuse by patient
- Caregiver abuse by family
- Patient abuse by non-caregiver family
- Non-family caregiver patient abuse
Intensifying care

- In home additional caregivers
  - Professional vs lay
- Adult day care
- Respite care
- Long term institutional care
End of life

• Advanced Alzheimer’s disease
• Advice for caregivers
  – Caregiver role after institutionalization
  – A special kind of grief
• Ongoing physician/caregiver relationship?
• Remember: don’t wait too long for palliative care, including possible hospice care.
Conclusions

• Care for patients with dementia must focus on the patient and the caregiver.
• Caregiver education is paramount duty of the primary care provider, the geriatric psychiatrist and the geriatric nurse.
• Caregivers must be supported and empowered.
• Direction should be empathetic but directive.
• Quality of life is the major goal; this includes caregiver appreciation of the illness, full knowledge of the natural history, exploration of care options and thoughtful prognostication.
• Caregivers are often lost in the struggle against dementing illness; this is worse than a double tragedy.
Final conclusions, what can I say?

• These are complex health care issues that require experience, a broad knowledge-base, major attitudinal skills and compassion.

• Sometimes innovation and ingenuity are needed.

• It also requires fortitude and support for health care providers – don’t forget that!

• Many important issues have not been covered
  – Nutrition, dry mouth, mucositis, skin breakdown, depression (suicide), advance directives, etc.

• Most importantly – go to the bedside, be there with the patient and the family
And finally...
Remember: You are a caregiver, too.
Questions?