Objectives

- Accurate assessment and diagnosis of the older person with cognitive loss
- Provide support and education for person with Alzheimer’s, family, and caregivers
- Describe particular issues of aging with regard to palliative care, including need for functional assessment, medication choice, and treatment of behavioral issues
- Create a framework to consider ethical issues

Objectives, cont.

- Improve palliative care and hospice care practice in assisted living and nursing facilities
- Discuss Avila Institute of Gerontology Palliative Care training for Residents with cognitive impairment
Good Palliative Care requires Good Geriatric Care

- Functional assessment and recognition of changes may be more important than diagnoses
- Cognitive decline can often be missed and/or ignored while attention focused on other medical problems
- Dementia may be misdiagnosed in setting of delirium or depression

Dementia is not a necessary part of aging...

- The development of a symptom or syndrome in an older person should not be automatically ascribed to dementia or aging
- Good palliative care requires accurate diagnosis to the extent possible
- Wrong to provide only comfort care, for example, to someone with a treatable depression or with hypothyroidism

Common Changes of Aging

- Accumulated changes of normal age lead to a loss of margin of safety
- Development of “homeostenosis” rather than homeostasis
- Increasing age, increased risk of injury, illness, and death
Differences in Illness Behavior and Presentation

- Uncommon presentations of common illnesses
- Non-specific signs and symptoms
- Easy to miss life-threatening illness if label as "old age" and do not pay attention to function
- Loss of functional abilities means need for evaluation and possible intervention
- This holds true in persons with cognitive decline...behaviors may be due to pain, fecal impaction, infection, change in thyroid function.

Vision and Hearing

- Cataracts are a true change of aging
- Glaucoma, macular degeneration, and diabetic retinopathy common causes of vision problems in older persons
- Presbycusis is common change in hearing with aging...progressive hearing loss in higher frequencies

Common Changes with Aging

- Vision loss from cataracts and macular degeneration
- Hearing loss from presbycusis
- Change in body composition and renal function
Common Changes with Aging, cont.

- Less muscle, less water, more fat: decreased lean muscle mass, increased percentage of body fat, decreased total body water
- Renal mass decreases about 25% with glomerular decrease about 40%; cortical nephron loss is greater than medullary nephrons...decreased renal blood flow with loss of cortical efferent arterioles and increased relative medullary blood flow
- Functional renal changes: Decreased GFR, diminished concentrating ability, changes in Cre clearance, alterations in thirst and predisposition to dehydration

“Pearls” on medications

- Caution with non-steroidal drugs: GI bleeding and renal failure.
- Use of acetaminophen sometimes surprisingly effective
- Lidocaine patch expensive but can provide relief
- Use of opioids: short versus long term, round the clock and prn

Thoughts about common medications

- Fentanyl patches: first thing people use when they don’t know what they are doing---the demerol of the 21st Century!
- Delirium and dementia: are the meds making things worse? Anticholinergic effects and/or akathesia?
- Haloperidol, risperidone, quietapine
- Atropine vs glycopyrrolate
- Lorazepam
Geriatric Syndromes

- Understand differences in illness behavior and presentation with aging and importance of functional changes
- Falls: understand key factors contributing to falls in older persons
- Incontinence: know the differential diagnosis incontinence
- Mental status changes: differentiate delirium from dementia

Falls

- With advanced dementia, may not know where feet are, unsure how to walk, can’t react if balance lost
- Falls can occur because of hypotensive or sedative effects of medication
- Decreases in blood pressure after meals and receiving meds
- Loss of strength in quadriceps and proximal muscle weakness

Urinary Incontinence

- Not due to old age
- Aging provides a series of common changes that can predispose
- Transient incontinence is usually treatable, established incontinence may be improved
- “Double incontinence” suggests a fecal impaction
**Mnemonic for New Onset Incontinence**

**“DIAPERS”**

- Delirium
- Infection
- Atrophy
- Pharmaceuticals
- Psychological
- Excess Fluid Output (CHF, hyperglycemia)
- Restricted Mobility
- Stool Impaction

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**Delirium versus Dementia**

- DELIRIUM: Decreased attention, visual hallucinations, acute onset, waxing and waning
- DEMENTIA: Attention preserved until late, hallucinations not common until late (exception can be Lewy Body Dementia), onset subacute to chronic, usually stable although will “sundown” with intercurrent illness, new meds, change in environment.

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**Making a diagnosis**

- Functional status and change over time...with delirium change is usually abrupt with dementia usually loss of IADLs over months or longer before recognized
- Dementia is diagnosed with deficits in two or more cognitive domains with preserved attention
- Alzheimer’s remains a diagnosis of exclusion
**Diagnosing dementia**

- >50% of persons with dementia (many mild, some moderate) have not been diagnosed by a physician
- 3-11% >65 and 25-47%>85 have dementia
- Cholinesterase inhibitors can slow decline in scores of cognitive change BUT no strong evidence of functional improvement
- Nothing halts advance of Alzheimer’s disease


**Psychiatric illness**

- Sudden changes in functioning in older persons (e.g., “new onset” bipolar illness or mania) likely represent delirium in the absence of a previous psychiatric history
- Depressed people often complain of memory problems and may have decreased attention and speed in performing tasks
- Many demented people have symptoms consistent with depression...treating the depression improves their mood but not their cognitive function

**Memory problems and dementia**

- Mild cognitive impairment
- Alzheimer disease
- Frontotemporal dementia
- Lewy body dementia
- Vascular dementia
DEMENTIA

There may be over 60 conditions that gradually destroy brain cells and lead to a progressive decline in mental function.

- Alzheimer’s disease
- Frontotemporal dementia (Pick’s disease)
- Dementia with Lewy bodies
- Vascular dementia (chronic low blood flow)
- Small or large strokes
- Multiple causes
- Parkinson’s disease
- Tumors
- Traumatic brain injury

Other common dementias include cognitive impairments common with Multiple Sclerosis; alcoholic dementia; syphilis; AIDS dementia.

Frontotemporal Dementia

- Variety of disease processes of the frontal lobes and front part of the temporal
- Many underlying diseases that can present as a frontotemporal dementia
- Pick’s disease is a specific disease

Pick’s disease

- Identified earlier than Alzheimer’s by Arnold Pick in Prague -- He described 2 patients with prominent behavioral and language impairment.
- Alois Alzheimer examined the brain and found “Pick’s Bodies” that are now called tau protein.
**Frontotemporal Dementia**

- Early Behavioral and Personality Changes and or changes in language and speech
- Their memory for day-to-day events may be strikingly preserved when compared with Alzheimer’s Disease

**Dementia With Lewy Bodies**

- Under the microscope the brain shows senile plaques of Alzheimer’s but far fewer neurofibrillary tangles. By contrast, they show the brain cell changes that are normally associated with Parkinson’s disease, that is a protein deposit referred to as a Lewy Body, named after its original discoverer.

**Vascular Dementia**

- Recurrent large or small strokes and nerve cell damage from disease in the small arteries to the central parts of the brain, called small arteries or Binswanger’s disease.
<table>
<thead>
<tr>
<th>Common Dementias: A Comparison of Symptoms, Treatment and other information</th>
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</thead>
<tbody>
<tr>
<td><strong>Alzheimer’s disease</strong></td>
<td>Insidious onset and progressive decline in cognition; remarkable memory loss</td>
</tr>
<tr>
<td>Cholinergic enhancers (cholinesterase inhibitors); disease modifying agents</td>
<td>Genetic risk factors identified</td>
</tr>
<tr>
<td><strong>Dementia with Lewy bodies</strong></td>
<td>Triad: Visual hallucinations; spontaneous Parkinsonism; fluctuating cognition (alterations of alertness and attention)</td>
</tr>
<tr>
<td>Cholinergic enhancers (cholinesterase inhibitors)</td>
<td>Neuroleptic sensitivity; paradoxical responses to various pharmacological agents</td>
</tr>
<tr>
<td><strong>Frontotemporal dementia</strong></td>
<td>Personality change &amp; language impairment more common than with AD; apraxia, impulsivity, impaired judgment &amp; social behavior, apathy, carbohydrate craving, manic states, or grandiose delusions</td>
</tr>
<tr>
<td><strong>Pick’s disease</strong></td>
<td>No current drug treatment</td>
</tr>
<tr>
<td><strong>Vascular dementia</strong></td>
<td>Stepwise deteriorating course; acute dysfunction of cognitive domains; focal neurologic signs; hyperreflexia, ataxia, gait</td>
</tr>
<tr>
<td>Identify and modify risk factors; physical therapy; gait analysis</td>
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**Treatment of Alzheimer’s Disease**


- Five components
  1) Neuroprotective strategies: Vitamin E 1000 IU bid/Memantine (Namenda)
  2) Cholinesterase inhibitors
  3) Interventions for behavioral disturbances
  4) Health maintenance
  5) Working with caregivers
Behavioral disturbances...

- Non-pharmacologic
- Atypical antipsychotic agents: risperidone, quetiapine, olanzapine
- Mood stabilizing agents for agitation: carbamazepine, divalproex
- Depression: SSRI’s and TCA’s...increased risk of anti-Ch side effects with latter

Health maintenance

- Influenza and pneumococcal vaccine
- Control of hypertension
- Vision and hearing, dental care
- ASA 81 mg/day if no contraindication
- Establishing advance directives and surrogate decision maker (Durable POA)

Alliance with caregivers

- Advance directives and financial planning
- Home safety, including guns
- Driving
- Safe Return/ Identification
- Referring caregivers for assistance, respite, support
Caring for Persons with Dementia in Assisted Living and Nursing Homes

- Accurate care planning
- Working with family and person
- Good relationships between hospice and residence staff
- Education for staff
- Developing checklists to ensure persons are adequately assessed
- Establishing clarity about DNR, DNI, and other treatment decisions

Carmelite Sisters for the Aged and Infirm Person Centered Care

- All Residents are individual unique human beings
- All residents are valued

Why Person-Centered Care?

- Shares in the healing ministry of Jesus
- Values the person you care for, the people who help you do it and the loved ones who trust you
- Validates each individual as a unique human being
Why Person-Centered Care?

- Develops relationships
- Concentrates on strengths
- Understands the person and the disease
- Knows when the person is talking and when the disease is talking

Mother Mary Angeline Teresa, O.Carm

“Bringing Christ means giving them His compassion, His interest, His loving care, His warmth morning, noon and night”.

Why Person-Centered Care

<table>
<thead>
<tr>
<th>It is our moral obligation</th>
<th>It develops relationships</th>
<th>It provides choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>We share Jesus’ healing ministry</td>
<td>Residents and Love Ones needs before our own</td>
<td>It gives control and independence</td>
</tr>
<tr>
<td>We are unique human beings</td>
<td>Values my opinion</td>
<td>It is includes all ideas</td>
</tr>
</tbody>
</table>
Mother Mary Angeline Teresa, O.Carm, Foundress of the Carmelite Sisters for the Aged and Infirm said in 1968

“Old age is a lonely period. At no time in a person’s life is kindness so much needed and appreciated. Efficiency is wonderful, but it should never replace kindness. All professional skill should stem from the kindness and compassion of Christ.”

Carmelite Sisters End of Life Care

• To address all aspects of End of Life Care with residents and loved ones to ensure each aspect is understood and clarified
• Practice ethical standards consistent with the values and principles inherent in the teachings of the medical and moral directives of the Roman Catholic Church.
• To be present with residents, loved ones, staff and other residents during the dying process.

Carmelite Sisters End of Life Care

• Provide holistic care through team effort and support that embraces the physical, spiritual, social, psychological, emotional needs to ALL who under our care.
• Recognize that life is precious and should be preserved whenever possible and that death is the prelude to eternal life.
• To be available for loved ones, staff other residents after death occurs.
Carmelite Sisters End of Life Care

- Provide ongoing training in all areas of Person Centered Care and Palliative Care
- Assess each resident’s domains of pain with appropriate tools
- Assess all environmental issues to ensure each resident receives optimal service in a “home.”

Communication

- Attention to cultural and linguistic abilities of resident or family
- Early stages of dementia can communicate their wishes for treatment
- Pay attention to nonverbal communication – and pay attention to staff’s nonverbal and verbal communication

Communication, cont.

- Advance planning involves resident, proxy, family, and care team
- Provide education about course of dementia and benefits and burdens of different care options
- Rules about hiring extra help, transfers to other facilities, and access to hospice services
- Timing of communication: regular, scheduled, and involving family and care teams
Decision Making

• Policies need to be clear in facility
• Asking about advance directives on admission
• Resident’s preferences regarding “DNR”, “comfort care only”, “DNH”, “DNI”
• Proxy decision makers

Decision Making, cont.

• Ongoing evolution of preferences, regular meetings, involvement of family and care team
• Planning care planning meetings...helping match plans to achievable goals

Care Provision, Coordination and Communication
When Residents Choose Hospice Services

• Communication between residence staff and hospice staff
• Integrating care plans
• Deciding who is primary source of information for family
• Policy for conflict resolution between hospice staff and residence staff
**Assessment and Care for Physical Symptoms, Including Pain**

- Must assess and treat, regular assessment is crucial
- Develop check list for direct care workers
- Consistent staff assignment, esp for those residents with limited verbal communication to provide more consistency in recognition of symptoms

**Assessment and Care for Behavioral Symptoms**

- Checklist of behavioral symptoms
- Differential diagnosis for changes
- Why are you using a psychoactive medication?
- Altering the care plan and environment:
  - tell persons what you are up to, providing companionship for the isolated, gentle music, attention to lighting, privacy

**Psychosocial and Spiritual Support of Residents and Family**

- QOL “for residents with dementia depends on the quality of the interaction and relationships they have with direct care staff.”
- Trying to make contact through significant parts of a person’s life—language, music, other senses
- Not leaving people alone to die
- Spiritual support, awareness of traditions, access to clergy as desired
- Space appropriate for quiet time, prayer, meditation esp. for family
Psychological and Spiritual Support of Resident’s Family

- Preparing for grief
- Dealing with guilt of proxy decision makers
- Support during active dying
- Education about dying process, including signs and symptoms
- Have a plan about who to notify, funeral home, period of time before personal items need to be cleaned out

Family Participation in Resident’s EOL Care

- Working with family in developing care plan and considering options with which they are comfortable assisting
- Facilitating communication among family and caregivers with a “Q and A” logbook or email communication
- Facilitating family presence when resident is actively dying
- Creating family support networks

Staff Training

- Develop a Curriculum for the Staff, can be given by residence leaders or by hospice
- Elements of the Curriculum
- Pairing experienced staff with new staff who are caring for persons with dementia and who are appropriate for palliative and/or hospice services
Acknowledgement of Death and Bereavement Services

• Planning for respect and compassion at time of death for resident, family, and other residents
• Memorial services for residents who have died
• Acknowledge staff bereavement
• Allow staff and residents to attend wake/funeral/memorial if at all possible

Summary: Excellence in Palliative Care for Persons with Dementia

• Attention to aging changes and accurate diagnosis
• Care with medications and assessment of symptoms
• Develop behavior management programs
• Use of medications for Alzheimer’s and behaviors
• Developing collaborative relationships with assisted living and nursing facilities.